A long road to recovery:
Well-being of PLHIV on ART in Lusaka, Zambia.

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Research Master Thesis

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Note: Cover Photograph by Anneke Veen. Picture was taken in Zambia near Chilonga in Northern Province.
Abstract

The HIV epidemic has affected, and continues to affect individuals, households, communities, and societies at large. With the introduction and rapid up-scaling of antiretroviral therapy (ART) in developing countries there is hope that many of the negative effects and impacts of the epidemic will be mitigated. Research thus far in resource limited settings, while still limited, has been positive with regards of ART on socio-economic conditions and quality of life both on an individual and household level.

The aim of this research project is to provide insight into the impact of ART on the well-being of HIV positive individuals and their households in Lusaka, Zambia. The study used a mixed method model whereby quantitative and qualitative data was collected simultaneously. Research was conducted in both 2010 and in 2012 in two urban areas in Lusaka, namely: Kalingalinga (research conducted in 2012) and Roma N’gombe (research conducted in 2010 and 2012). In these two areas Home Based Care (HBC) projects and their clients were studied. Three theoretical models were used in the study (the Ecological Systems Theory, the Livelihoods Pentagon, and the Body, Mind and Spirit model from the public health Ecological Model of Health).

The data collected provides insight into the socio-economic situation of people living with HIV (PLHIV) and their households and the physical and mental health of PLHIV. This research observed differences between the two areas, whereby Kalingalinga had higher socio-economic outcomes but lower mental health outcomes than Roma N’gombe. Evidence from this research suggests that this difference stems from the difference in external support structures available in the two areas. PLHIV in Roma N’gombe are part of a strong HBC project that offers guidance and support on a number of levels. The situation in Kalingalinga, while being the economically better area, is less positive with regards to the external support that PLHIV are offered at the HBC project.

The study shows the importance of the temporal context of PLHIV and their households and allows for an examination of the recovery process after the initiation of ART. The individual trajectories of PLHIV, thus, impact their recovery process and success. For those who start with ART at a late stage of infection their well-being (for example: income levels, job type, and mental- and physical-health) is worse than for those who start with ART in an earlier stage of infection. In addition, not only are the recovery processes more difficult and longer for people who start with ART in a late stage of infection but also their overall socio-economic outcomes remain lower.

This study adds an interesting dimension to the already existing reasons to start with ART in an early stage of infection. Medical literature shows that early initiation of ART leads to better physical health outcomes for PLHIV and that it is an effective prevention strategy. The main conclusion of this research is that early initiation of ART leads to maintaining socio-economic status for PLHIV and their household. Moreover, early initiation of ART leads to overall better socio-economic outcomes in the long term.

Key words: Lusaka, Well-being, People Living with HIV (PLHIV), Antiretroviral Treatment (ART), Mixed-methods, Trajectories.
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### Abbreviations

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<th>Full Form</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
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<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
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<tr>
<td>ARV</td>
<td>Anti Retro Viral</td>
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<tr>
<td>cART</td>
<td>comprehensive Antiretroviral Therapy</td>
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<td>CHBC</td>
<td>Community Home Based Care</td>
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<td>CO</td>
<td>Coordination office</td>
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<td>FBO</td>
<td>Faith Based Organisation</td>
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<td>GRZ</td>
<td>Government Republic of Zambia</td>
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<tr>
<td>HBC</td>
<td>Home Based Care</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>JCTR</td>
<td>Jesuit Centre for Theological Reflection</td>
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<tr>
<td>LCC</td>
<td>Lusaka City Council</td>
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<tr>
<td>LTFU</td>
<td>Loss To Follow Up</td>
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<tr>
<td>MDG</td>
<td>Millennium Development Goal</td>
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<tr>
<td>MsF</td>
<td>Médecines Sans Frontières</td>
</tr>
<tr>
<td>OVC</td>
<td>Orphans and Vulnerable Children</td>
</tr>
<tr>
<td>PEPFAR</td>
<td>The United States President’s Emergency Plan for AIDS Relief</td>
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<tr>
<td>PLHIV</td>
<td>People Living with HIV</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
</tr>
<tr>
<td>RDC</td>
<td>Residents Development Comity</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV and AIDS</td>
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<tr>
<td>UNDP</td>
<td>United Nations Development Program</td>
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<tr>
<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<tr>
<td>VC</td>
<td>Volunteer Care-givers</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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Chapter 1 – Introduction

1.1 Introduction

With an estimated 34 million people worldwide living with HIV at the end of 2011 and 2.5 million new HIV infections in the year 2011 alone (UNAIDS, 2013:8), the HIV pandemic remains one of the main health and human development challenges we face today (Edström & Samuels, 2007:1).

Sub Saharan Africa is the home to 12% of the world’s population, yet, in mid-2010 it was estimated that 68% of all PLHIV were residing in this region (UNAIDS, WHO, & Unicef, 2011:24). Nearly one in twenty of the adults (4.95%) in this region are living with HIV (UNAIDS, 2012:8). There were 1.9 million new HIV infections in this region in 2010 alone, this “represented 70% of all the people who acquired HIV infection globally”. As such, “Sub-Saharan Africa continues to bear a disproportionate share of the global HIV burden” (UNAIDS, WHO, & Unicef, 2011:24).

“AIDS has claimed at least 1 million lives annually in Sub Saharan Africa since 1998” (UNAIDS, WHO, Unicef, 2011:25). The death toll peaked at 1.7 million lives in the year 2005. However, the number of people dying from AIDS related causes has decreased steadily since then, as ART started becoming widely available from this time onwards (UNAIDS, WHO, & Unicef, 2011:2). In Sub Saharan Africa an estimated 1.2 million PLHIV died in 2011 (UNAIDS, 2012:15), this is 32% fewer than in 2005 (UNAIDS, 2012:12).

In 2004 the access to antiretroviral therapy was significantly expanded and this “has helped to reduce the number of people dying from AIDS-related causes” (UNAIDS, WHO, Unicef, 2011:19). In 2003 an estimated 400,000 people had access to ART in low and middle income countries, in 2010 this number had increased to 6.65 million people, which is a 47% coverage of people eligible to therapy (UNAIDS, WHO, & Unicef, 2011:2). The number of people who are newly infected in Sub Saharan Africa appears to be decreasing. UNAIDS, WHO, & Unicef (2011:24) estimate that “about 16% fewer people acquired HIV infection in 2010 than in 2001”1 (UNAIDS, WHO, & Unicef, 2011:24). This decrease in incidence may in part be explained by the now mounting scientific evidence that “suggests that increased access to ART is also contributing substantially to declines in the number of people acquiring HIV infection” (UNAIDS, WHO, Unicef, 2011:2).

Sub Saharan Africa comprises of a vast number of countries and the extent to which individual countries have been affected by the HIV epidemic varies. Differences can even be seen within countries; differences in prevalence rates between urban and rural areas are the most commonly mentioned in this regard. Zambia is one of the countries in Sub Saharan Africa that has been and continues to be severely impacted by the effects of the HIV epidemic.

The impact of HIV is not just on an individual level nor should it be seen as merely a physical health problem. In Zambia the effects of HIV is impacting children, individuals, families, communities, and even society as a whole. The epidemic hit the country early (mid-eighties) and strong compared to other countries in the region. The HIV epidemic is said to be “the most serious threat to the development agenda in Zambia” (UNAIDS, 2008a:1). Seeing that the epidemic strikes the most economically productive members of society it is not surprising that it brings with it profound social and economic consequences (Mwakalobo, n.d.:51; D’Adda et all, 2009:180).

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1 In 2001 an estimated 2.2 million [2100000-2400000] people were newly infected, compared to 1.9 million [1700000-2100000] new HIV infections in 2010 (UNAIDS, WHO, Unicef, 2011:24).
The global introduction of ART has reduced the number of people dying from HIV related conditions. This effect is also visible in Zambia. It is estimated that there were 970,000 PLHIV in Zambia in 2011 (UNAIDS, 2013:7). In 2005 70,685 people died on AIDS-related deaths, in 2011 this was 22,800 which represents a 56% decline in AIDS-related deaths in Zambia (UNAIDS, 2013:8). Since 2004-2005 an enormous increase in the number of people in Zambia receiving ART has been seen.

In 2009 there were an estimated 350,000 people needing ART (based on WHO 2010 guidelines) in Zambia, this was 510,000 in 2011 (UNAIDS, 2012:A66). In 2010 there were 344,407 people reported to be receiving ART in Zambia, this represents an estimated ART coverage of 72% (UNAIDS, WHO, Unicef, 2011:193). In 2011, this coverage further increased to 82% (UNAIDS – AIDSinfo, nd), which is a huge increase considering it was only 13%\(^2\) in 2004 (Egger et al., 2005:510).

It is suggested that the provision of ART may have profound impacts on socio-economic wellbeing and offset negative impacts of HIV at a household level. The effects of ART on the physical health of people has been well documented elsewhere (see: Ferradini et all (2006); Ivers et al (2005); Laurent et al (2002)) with positive treatment success “with regard to survival, physical health, and immunological responses” (Wagner et al, 2009:793). The broader effects of ART on individuals and their households, however, is far less clear and only limited research into socio-economic effects and well-being has been conducted. This thesis hopes to provide a more holistic view of the impacts of ART on PLHIV and their households in Lusaka, Zambia.

This research has the following aim:

To provide an insight into the impact of ART on the well-being of HIV positive individuals and their households in Lusaka, Zambia.

This introductory chapter provides a situation sketch of Zambia and a brief outline of the impacts of the HIV epidemic on the country. HIV is having far reaching consequences on all aspects of Zambian society, an overview of this will be given in section 1.3. This introductory chapter also serves as background information with regards to ART (section 1.4) and more specifically the introduction and situation of ART in Zambia (section 1.5). Finally section 1.7 provides an outline of the set-up of this thesis.

1.2 Background Zambia

The Republic of Zambia, formerly known as Northern Rhodesia, gained its independence on the 24th of October 1964. Cecil Rhodes obtained mining concessions in 1889 and soon after sent settlers to the area. The region was ruled by the British South Africa Company, established by Rhodes, until 1924 after which it was taken over by the United Kingdom. It remained a British protectorate until Zambia gained its independence. Zambia is a landlocked country located in Southern Africa, it has a tropical climate and consists mostly of high plateau. Zambia covers a total of 752,612 km\(^2\) ranking it the world’s 39th largest country in the world. There are eight countries bordering it, namely: Angola, Democratic Republic of Congo, Tanzania, Malawi, Mozambique, Zimbabwe, Botswana, and Namibia. In 2010 the country had 13,089,000 inhabitants of which 39.2% lived in urban areas (UNdata, nd). The proportion of people living in urban areas had been declining since the 1970’s. During the 1969-1980 period the population living in urban areas increased from 29.4% to 39.9% (CSO, 2000:xi). After this urbanisation no longer

\(^2\) This coverage is based on the 2010 WHO guidelines for Antiretroviral Therapy.

\(^3\) Best coverage estimate based on the midpoints of the number of people receiving antiretrovirals. Adapted from WHO’s “3 by 5” Progress Report, December 2004. (See WHO, 2005)
accelerated. In 1990 the percentage of people living in urban areas had already declined to 39% and continued to decrease to 36% in 2000 (CSO, 2000:xii). Recent figures from the 2010 census in Zambia indicate that this trend is reversing and the percentage of people living in urban areas is increasing.

Copper mining and refining, which started in the 1920s constitutes the largest industry in the country and forms the basis for its economy. The world market for copper has determined Zambia’s fate for almost a century now (Dietz et al., 2008:71). In the first decade after Zambia’s independence the economy grew rapidly due to high copper prices. In 1975 the price dropped drastically and Zambia’s economy came in a recession. By 1998 the output of copper had fallen to a significantly low level after “a 30-year decline in output due to lack of investment, low copper prices, and uncertainty over privatization” (UNCTAD, 2012:2). After the privatization of the industry, in 2002 the copper production started to rebound. In addition the world copper market also improved leading the sector to grow by 7.4% in 2010 (UNCTAD, 2012:2).

The country is divided administratively into ten provinces and 95 districts. Out of these ten provinces most densely populated and most urbanised provinces are Copperbelt and Lusaka Provinces. The remaining provinces, Central, Eastern, Northern, Luapula, North-Western, Western, Southern, and Muchinga, are predominantly rural provinces. Lusaka is the capital of Zambia and is home to 1,742,979 people (CSO, 2011:41).

Zambia is located in the southern tropics, and it is this geographical location in combination with its altitude that causes it to have a moderate tropical climate. Three distinct seasons are present, namely a warm wet season

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4 Zambia until recently had 9 provinces, after the elections in 2011 the new president announced on October 14th 2011 that he planned to create a tenth province to be named Muchinga. The tenth province was to comprise of a number of districts and effectively split up Northern province. “Muchinga Province comprises the districts located east of Chambeshi River, namely Mpika, Chinsali, Izoka, Nakonde and Mafinga” (MLGH, 2012). There are some rumours that a district from Eastern Province, namely Chama, may also become part of the new province.

5 Zambia until recently had 72 districts, these were administratively divided into 4 City Councils, 14 Municipal Councils and 54 District Councils. Since the elections in 2011 the new president Michael Sata has been creating new districts. The exact number of districts now fluctuates as new districts are being created all the time. Currently (04-06-2012) in addition to the original 72 districts an additional 23 exist, namely: Rufunsa, Sibuyunji, Chembe, Zimba, Vubwi, Langa, Pembia, Chilanga, Chikankata, Chirundo, Mulobezi, Nsama, Sinda, Chipili, MWansambombwe, Mafinga, Ikelengi’s, Nkeyema, Limulunga, Mwandi, Luano, Chisamba, Chitambo. This as such is still subject to change.
from November to April, a cool dry winter from May to August, and a hot dry season during September and October.

Zambia has a population that is almost completely (98%) descendant of Bantu-speaking migrants, divided into 70 plus ethnic groups (New Internationalist, 2007:580). The largest of these ethnic groups are the Bemba, Kaonde, Lozi, Lunda, Luvale, Nkova, Nyanja/Chewa, Tonga, and Tumbuka. The official language of Zambia is English, in addition, since 1991, there are seven recognised national languages, namely: Bemba, Nyanja, Tonga, Lozi, Kaonde, Luvale, and Lunda (Marten & Kula, 2008:189).

In the early 1970's Zambia was classified, by the World Bank, as a country in the middle range of middle-income countries. However, Zambia “had sunk into the ever-deeper ends of the lists of low-income countries in the early 2000's” (Dietz, 2008:70). The price for copper on the copper market has in recent years increased dramatically. In 2011 the World Bank announced that it would re-classify Zambia as a middle-income country. They said “the upward adjustment in Zambia's income growth is a result of foreign aid-driven interventions and surging prices of copper” (Lusaka Times, 2011). Similarly the UNDP (2011:12) said “the recent resurgence of consistent economic growth gives hope that Zambia could improve its human development status to pre-1980 levels and higher”. However despite these positive remarks and the fact that Zambia has now been economically reclassified, Zambia continues to belong to the group of countries scoring low amongst the human development indexes. In 2012, the country had a Human Development index of “0.448 placing – in the low human development category – positioning the country at 163 out of 187 countries and territories” (UNDP, 2013). Zambia’s HDI value increased 11% between 1980 and 2012, from 0.405 to 0.448 (UNDP,2013). It is estimated that between 2000 and 2009 64.3% of the population was living below the poverty line of US$1.25 a day\(^6\) and 59.3% were living below the national poverty line\(^7\) (UNDP, 2011:144).

1.3 HIV in Zambia

Zambia has one of the highest burdens of HIV in the world and AIDS related deaths continue to be one of the main causes of death; in the year 2011 an estimated 31,282 people died of AIDS related diseases (UNAIDS, 2013:8). In 2011, Zambia had an HIV adult (15–49) prevalence rate of 12.5, an incidence rate\(^8\) of 0.8, and an estimated 51,000 new infections (UNAIDS – AIDSinfo, nd). In 2011 it was estimated that a total of 970,000 people were living with HIV in Zambia (UNAIDS – AIDSinfo, nd).

Prevalence rates vary across the country. The main variations can be seen geographically, between different age groups, and between men and women. There is a stark difference between rural and urban areas with the lowest prevalence rate being 6.8 in Northern Province and the highest (20.8%) in Lusaka Province. These differences have been depicted in map 1.2\(^9\).

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\(^6\) Population below PPP $1.25 a day: Percentage of the population living below the international poverty line $1.25 (in purchasing power parity terms) a day.

\(^7\) Population below national poverty line: Percentage of the population living below the national poverty line, which is the poverty line deemed appropriate for a country by its authorities. National estimates are based on population-weighted subgroup estimates from household surveys.

\(^8\) "ADULT (15–49 YEARS) INCIDENCE: To calculate the adult HIV incidence, the estimated number of adults (15–49 years) newly infected with HIV in 2009 was divided by the 2009 adult population (15–49 years) not infected at the start of 2009” (UNAIDS, 2010:179).

\(^9\) Maps and data reflecting Muchinga Province are not yet available and have as such not been depicted in this map.
The adult prevalence in Zambia remains high although it appears to have stabilised in recent years. The number of AIDS related deaths increased steadily until the year 2003 after which it started to decrease. In 2003 a total of 75,000 people died of AIDS related diseases; this was 62,000 in 2007 and as mentioned previously had further decreased to 40,000 by 2009 (UNAIDS – AIDSinfo, nd). This decrease can be accredited to the introduction and rapid upscale on ART in Zambia (this will be further discussed in the sub chapter about ART in Zambia). The above however also implies that with a decrease of the number of people dying, and a continuation of new infections, the prevalence will eventually increase. UNAIDS (2010:68) has announced that the incidence in Zambia declined by more than 25% between 2001 and 2009.

The HIV epidemic is clearly having a huge impact on Zambia. Barnett & Whiteside (2002:5) tell us that the HIV epidemic is affecting not only the health of individuals but is also affecting the welfare and well-being of households, communities and ultimately entire societies. The epidemic strikes the economically productive members of society. As such it is not surprising that it brings with it profound social and economic consequences (Mwakalobo, n.d.:51; D’Adda et al, 2009:180).

The main characteristics of the HIV epidemic in Zambia and its impact can be described as follows:

- There were approximately 980,000 people living with HIV in Zambia in 2009 (UNAID, 2010:180). Of these 860,000 were adults (15+ years) (UNAIDS, 2010:180) and 490,000 were women (UNAIDS, 2010:182). This means 56% of all adults living with HIV in Zambia is female; women are disproportionately affected and impacted by HIV. Particularly young women (15-24) are disproportionately affected; in 2009 they were more than twice as likely to be HIV positive than men in

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10 Prevalency of HIV is the proportion of the population aged 15-49 years who are HIV infected. The population of Zambia has increased over the years, meaning that if the prevalence has remained the same (or decreased), in actual numbers the number of people who are HIV positive has increased (or remained the same). As such, this stabilising of the HIV prevalence can be accredited to, in part, the increase in the population.

11 Nsubuga et al (2013:562) state that “Because the prevalence of HIV depends on the incidence and duration of infection, as people with HIV infection on ART live longer, the duration of HIV infection increases, and HIV prevalence tends to increase”. The discussion, as mentioned previously, regarding HIV prevalence, and incidence, is highly problematic and is not within the scope of this thesis. For more information see Nsubuga et al (2013).
the same age category (prevalence for women in this age group was 8.9 compared to 4.2 for men (UNAIDS, 2010:183)

- HIV in Zambia is not primarily a disease of the poor, according to AVERT (nd) “HIV in Zambia does not primarily affect the most underprivileged; infection rates are very high among wealthier people and the better educated”.

- In 2009 UNAIDS (2010:186) estimated that there were 690,000 orphans in Zambia as a result of the HIV epidemic. The HIV epidemic is strongly affecting children. In addition 120,000 children are estimated to be HIV positive (UNAIDS, 2010:182).

- HIV also impacts the elderly disproportionately. In a publication from HelpAge (2008:2) the following is said “HIV is causing a shift in household structure and responsibilities. At a time in their lives when many older people might expect to be supported and cared for by their own children, a growing number are taking on caring roles for younger adults living with HIV, and for the orphans and vulnerable children they leave behind.” Households where elderly are taking care of their grandchildren because the middle generation passed away are known as skipped-generation households. It is increasingly becoming clear that there are a large number of these type of households and that they are very vulnerable and face a large number of difficulties (see: Reijer, 2013).”

- HIV strikes the most economically active part of the population. Households as such find themselves losing chief earners. With the coming of ART this may in part be avoided, however the physical strength of PLHIV on ART does diminish; “patients reported that their physical strength is not as good as it was prior to their illness” (Reijer, 2010:33). A diminished capacity to work will also result in a decrease of household income.

- PLHIV suffer stigmatisation (including self-stigmatisation), income loss, poverty, and often discrimination and abandonment.

- Zambia is in the midst of a human resources crisis (UNAIDS, 2008a:1). This is particularly apparent in the health sector. The health sector in Zambia has “a dire shortage of health workers, with less than a third the doctor—patient ratio recommended by WHO” (Schatz, 2008:638). This shortage can be explained by a number of factors “including an exodus of trained professionals to other countries in Africa and overseas, an equally complicated internal brain drain, an outdated medical-training infrastructure, faulty government management, and the effects of HIV/AIDS. The result is a health workforce that is growing far too slowly, and in some categories, such as doctors, declining” (Schatz, 2008:638). In addition the HIV epidemic has affected the performance of the health system by “increasing demand for services in both quantity and complexity and by reducing the supply of services by its impact on the number and performance of the health workforce” (Makasa, 2008:82). In addition “The shortage poses a particular challenge to the national HIV/AIDS strategic plan as short-staffed government and church-run health clinics struggle to increase the number of people on antiretroviral therapy” (Schatz 2008:638).

- The HIV epidemic has disrupted the extended family system in Zambia. It is important to realise the breadth of the epidemic in the sense that not only is it increasingly causing death among adults, infants and young children but that it is also “slowly impoverishing and dismembering families” (Donahue, 2005:39). Families and communities (including extended families and extended-extended families) are carrying the gross of the social and economic consequences of the epidemic and it is here that the epidemic is taking its greatest toll (Over, 1998)

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12 “Estimated number of children (0–17 years) [...] who have lost one or both parents to AIDS” (UNAIDS, 2010:179).
13 The immediate extended family comprises the uncles, aunts, cousins, or grandparents on both sides of the marriage. Beyond this close kin, there are other relatives – twice or even three times removed – who are also part of this extended family or clan (Foster et al, 2005:17-18).
14 In Africa, the community is a kind of “extended-extended family” (Foster et al, 2005:16).
1.4 ART: what it is and what it does

The human immunodeficiency virus (HIV) epidemic started in the early 1980’s. HIV is a retrovirus that infects particular CD4 cells\textsuperscript{15} of the immune system. After infection individuals go through a latent stage, during which their health gradually declines. Gradually the infection progresses, the immune system is weakened and the individual becomes more and more susceptible to infections. Without treatment, this process continues and HIV progresses into acquired immunodeficiency syndrome (AIDS); “a stage associated with substantial weight loss (wasting) and opportunistic infections such as tuberculosis (TB) and pneumonia” (d’Adda et al, 2009:183). A person goes through a number of stages and the term AIDS applies to the most advanced of these stages. This process can take many years and people may often not even be aware of their HIV status for quite a number of years. In developing countries the median time for HIV to progress into AIDS is estimated to be 9.4 years (Morgan et al, 2002:597), and following this the median survival time after developing AIDS are reported to be between 5.1 months (Chequer et al., 1992:486) and 9.2 months (Morgan et al, 2002:597). It should be noted that people don’t die directly of AIDS. Opportunistic infections are generally the cause of death in AIDS cases.

Antiretroviral Therapy (ART\textsuperscript{16}) enables PLHIV to now live longer and healthier lives. ART is not a cure for HIV but it does “prevent the development of AIDS” (UNAIDS, 2009:1). UNAIDS (2009:1) explains with regards to HIV treatment “They can stop the virus being made in the body and this stops the virus from damaging the immune system, but these drugs cannot eliminate HIV from the body”. ART can slow down, stop, and reverse the disease progression by decreasing an infected person’s viral load. Realising that ART is not a cure it is important to note that people will need to continuously take ART, for the rest of their lives.

ART consists of the use of at least three antiretroviral (ARV) drugs and this “triple-drug combination antiretroviral (ARV) therapy has remarkable effects on the lives of people living with HIV” (Grubb et al, 2003:1). Already after two years of ART provision in South Africa in 2004 Coetzee et al (2004:887) state that “the benefits of antiretroviral therapy (ART) at an individual level are incontrovertible”. HIV is a very active ‘smart’ virus; it “makes lots of copies of itself that then damage the body’s immune cells” and at the same time it “quickly adapts to whatever medicines are being taken as it tries to change itself through mutations” (UNAIDS, 2009:1). ART uses a triple drug combination which “makes it harder for the virus to adapt and become resistant” (UNAIDS, 2009:1).

HIV, as mentioned previously, is able to adapt itself to medications and through mutations changes itself to become resistant against the medication. When this happens the virus can start to reproduce itself again and attack the immune system, it is at this time that the regimen of medications will need to be changed. UNAIDS (2009:3) explains that the first combination of drugs that a patient takes is usually called the first line regimen and that “when this no longer works to block HIV, another regimen made up of new medicines is needed […] and is called the second line regimen”. Usually the first line regimen will work for quite a number of years before the second line regimen is needed. Following the second line a third line or salvage cocktail of medicines may follow. But, as is explained in the next chapter the availability of this third line (and in some cases even second line) is still limited in low- and middle- income countries.

\textsuperscript{15} The CD4 cells can be seen as the managers of the immune system.

\textsuperscript{16} “The term antiretroviral therapy refers to a triple or more antiretroviral drug combination. Suboptimal regimens are mono-therapy and dual therapy.” (UNAIDS, 2011a:7)
Adherence to ART is of vital importance, adherence levels of lower than 95% are associated with the development of viral resistance to antiretroviral medications (Nachenga et al., 2007). Only when high adherence levels (i.e. over 95%) are reached the full benefit of the ART can be expected (Paterson et al. 2000; Mannheimer et al., 2002; Bangsberg et al., 2000; Howard et al., 2002; McNabb et al., 2001; Gifford et al., 2000; Haubrich et al., 1999; Ickovics et al., 2002; Nieuwkoop et al., 2001; Walsh & Sterr., 2002). Additionally Alcorn (2007) explains that resistance to the ARVs that are part of the first line regimens that are taken in resource-limited settings can develop very easily if doses are missed. As such the higher the adherence the less likely and the longer it takes before resistance is developed. Considering the limited access to second and third line treatments in resource limited settings it is of vital importance that a high adherence is maintained.

UNAIDS (2009:3) explains, in simple terms, what ARVs are and how ARVs work:

“Antiretroviral drugs are used in the treatment and prevention of HIV infection. They work against HIV by stopping or interfering with the reproduction of virus in the body. Inside an infected cell, HIV replicates and produces lots of copies of itself, which can then go on to infect other healthy cells within the body. The more cells HIV infects, the greater is its impact on the immune system, and the more severe the deficiency in the immune system it produces (immunodeficiency). Antiretroviral drugs interfere with the way HIV makes copies of itself and the way it spreads from cell to cell. There are several different classes of drugs.”

All ARVs have side effects. Most of these side effects are temporary and are seen at the beginning of the therapy. These side effects include: nausea, vomiting, and headaches. However, serious side effects and even fatal side effects can occur over time. In addition some “specific ARV medicines cause longer term changes in body shape and the distribution of fat within the body” (UNAIDS, 2009:2).

While it is vital for people who need ART that it is available there are other elements of care that are also important for PLHIV. In order for PLHIV to maintain a high quality of life access to good nutrition, safe water, and basic hygiene are also of great importance. UNAIDS (2008b:1) explain that in order to achieve the full benefits of ART an adequate dietary intake and absorption are essential. In addition survival rates amongst patients that begin with ART without adequate nutrition are lower (ibid). Finally the importance of psychosocial support and counselling for PLHIV should not be overlooked. In terms of adherence, both nutritional intake – side-effects may be reduced when medicine is taken with food and ART may increase appetite (ibid) – and psychosocial support and counselling, is found to help achieve a high adherence. Psychosocial support and counselling is also important for a number of other reasons. WHO (nd [Online]) explains that next to the direct impact psychosocial support and counselling can have on adherence there are a number of other things that should be considered. HIV impacts all dimensions of a person’s life (physical, psychological, social, and spiritual) and through counselling and social support people can be assisted to “cope more effectively with each stage of the infection” in addition it “enhances quality of life” (ibid). Furthermore “With adequate support, PLWHA are more likely to be able to respond adequately to the stress of being infected and are less likely to develop serious mental health problems” (ibid). Finally it is also argued that psychosocial support and counselling can assist individuals and their households “in making informed decisions, coping better with illness and dealing more effectively with discrimination” (ibid).
1.5 ART in Zambia – Past, present, and future

The introduction of ART in Zambia started around 2004. It should be noted that ARVs were already available in Zambia since 2001, however, these drugs were only affordable to a very select part of the population. Cost sharing\(^{18}\) was introduced, by the government of Zambia, in 2002 on a very small scale. At the time, free provision of ART was also started on a small scale by a number of foreign aid organisations, such as Misereor\(^{19}\) and MsF (Médecins Sans Frontières). Now ARVs have been made available free of charge\(^{20}\) all over Zambia through organisations such as PEPFAR (The United States President’s Emergency Plan for AIDS Relief) and Global Fund (The Global Fund to Fight AIDS, Tuberculosis and Malaria). Having said this it is important to note that this does not mean that everyone in need of ART is receiving it. In 2010, 72% of the people in Zambia who were in need or were eligible for ART were receiving it (UNAIDS, WHO & Unicef, 2011:98).

The response of the Zambian government is remarkable in terms of their ART policies and in many ways should be seen as applaudable, particularly in comparison to other countries in the region. An article by Ford (2012) titled “The past, present and future of affordable antiretroviral therapy in Africa” that focuses on the “past, present and future” of ART in Zambia provides an excellent overview.

“In 2002, the Zambian government took an important decision to provide low cost, antiretroviral triple therapy (ART) to respond to the high burden of disease caused by HIV/AIDS [...] To reduce the cost of treatment, the government announced that it would import generic versions of ART from India [(Zulu et al 2004)]. At the time there was considerable debate, much of it driven by vested interests, around the safety, efficacy and legality of generic antiretroviral drugs [(Ford & Hoen, 2002)]. But with proprietary triple therapy at the time costing more than three times the generic equivalent [(MSF 2011)], the government pressed ahead, noting that they would collect comparative safety and efficacy data [(Zulu et al 2004)].

[...] Amid the ever accumulating data describing the clinical and public health benefits of providing ART, it is easy to lose sight of the fact that prior to ART people presenting with AIDS-defining illness in resource limited settings could only expect to live ~6 months [(Kitayaporn et al, 1996; Chequer et al, 1992)]. Zambia’s decision to respond early to the HIV/AIDS epidemic has undoubtedly saved thousands of lives and has also resulted in a national programme that boasts one of the highest rates of treatment coverage in Africa. As of the end of 2011, ART coverage in Zambia was estimated at 72%, far higher than the average of 48% for low- and middle-income settings, and higher in absolute numbers than any developed country: there are more people on antiretroviral therapy in Zambia (283,863) than the USA (268,000) [(UNAIDS, WHO & Unicef, 2011)].” (Ford, 2012: 460)

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\(^{18}\) Cost sharing means that the total cost of an intervention in health is shared between the provider (government) and the receiver (patient).

\(^{19}\) Development agency of the German Catholic Bishop’s Conference

\(^{20}\) ARV is now free of charge, however, in some places people continue to have to pay for tests necessary for proper treatment, for example CD4 counts. Additionally it should not be forgotten that there are also other costs related to taking ARVs, such as transport costs, higher expenditures in food because of necessary diet changes, etc.
Not only was the country’s response earlier than other countries in the region it was also a bold decision. Zambia has continued to show a proactive approach towards ART.

"The country is also notable in having been one of the first in Africa to move towards providing tenofovir as first-line therapy. This policy shift, which was implemented 2 years before it was recommended by the WHO, has subsequently been supported by programme data showing better tolerability. And last year the government continued its tradition of acting ahead of international recommendations by releasing guidance for early initiation ART in serodiscordant couples to reduce HIV transmission, following recent evidence of preventive benefit." (Ford, 2012:460).

While Zambia has an estimated ART coverage of 72% for the entire population there is a huge difference in coverage for children and adults: estimated ART coverage among children in December 2010 was only 26% while that for adults was 84% (UNAIDS, WHO & Unicef, 2011:163). There is also a difference between the number of men and women receiving ART in 2010, where 42% of the people in Zambia receiving ART were male and 58% female (UNAIDS, WHO & Unicef, 2011:200). However, this is the same pattern that was seen in relation to differences in prevalence and as such the ART coverage between men and women is more or less the same. Coverage below the age of 15, for male and female children, is almost equal (GRZ, 2012:36).

The number of people receiving ART in Zambia has increased dramatically since 2005. According to GRZ (2012:36) this would mean that 90% of the adults in need of ART received this in 2011.

The effects of ART have been described by Ford (2012:460) as follows:

"Widespread access to ART has been demonstrated to yield substantial medical and public health benefits in terms of reduced mortality, morbidity and transmission. In the absence of a cure HIV/AIDS is a chronic disease, yet with effective treatment people with HIV/AIDS in Africa can expect to enjoy a relatively normal life expectancy. And in the absence of an effective vaccine, ART has proven to be the most effective biomedical intervention to prevent HIV transmission." 

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21 It should be noted that the price at the time for these drugs was three fold compared to the at that time advised WHO recommended drugs and that this shift had considerable benefits for patients.

22 A serodiscordant couple is a one in which one partner is HIV positive and the other is HIV negative.

23 In 2005 there were 51,764 adults on ART in Zambia, in 2008 this number increased to 200,891, this further increased to 319,101 by 2010, and in 2011 there were 385,498 adults on ART in Zambia (GRZ, 2012:36).

24 Less data related to children in need of ART and ART coverage exists. In Zambia, an estimated 98,000 children (aged 0-14) were in need of ART and the estimated ART coverage rate amongst children(aged 0-14) was 31% in 2011 (UNAIDS – AIDSwinf, nd).

25 In a recent study involving 1763 serodiscordant couples in which HIV-1–infected participants had a CD4 count of 350 to 550 cells per cubic millimeter ([1 cubic millimeter ~ 1 microliter]), there was a relative reduction of 96% in the number of linked HIV-1 transmissions resulting from the early initiation of antiretroviral therapy, as compared with delayed therapy"
In Zambia we can see that since the introduction and rapid up-scale in 2004-2005 of ART the number of people dying due to AIDS related causes has been decreasing. This trend can be seen in the chart below:

![Antiretroviral treatment scale-up versus AIDS deaths](image)

*Figure 1.4: Number of people on ART versus number of deaths due to AIDS in Zambia (adults and children)*

Ford (2012:460) also mentions that ART is preventing HIV transmission. This may, in part, explain the previously mentioned decline in incidence in Zambia.

Zambia aspires to provide universal treatment access in which ART is equally available to everyone who is clinically eligible (AVERT, n.d.). Currently, a number of schemes are making it easier for particular groups to gain access, these include: “civil servants, teachers, university students, and mother and child (through “PMTC Plus”)” (AVERT, n.d.). There are also some privately run schemes. These exist mainly in mining companies (AVERT, n.d.). Access to treatment is still unequally distributed where it is “a great deal easier for city-dwellers than for those living in rural areas” (AVERT, n.d.).

Zambia, as mentioned previously, continues to face a human resource crisis in the health sector. AVERT (n.d.) explains how the “treatment programme’s greatest handicap is the inadequacy of the healthcare system, which suffers from high patient numbers, lack of physical space and infrastructure, and – most critically – too few staff” (for more information on the human resource crisis in the health sector see section 1.3 on “HIV in Zambia”).

Clearly ART is having enormous impacts in Zambia and a lot of progress on the up-scaling of ART has already been made. However, Ford (2012:460-461) explains:

“[...] these benefits will only be guaranteed over the long term if countries are able to continue to improve treatment coverage while at the same time ensuring that those on treatment remain adherent to an effective regimen. The continued availability of affordable, effective ART is central to achieving these goals. However, the political struggle to secure access to affordable medicines is far from over.

(Cohen et al. 2011:503). In other words, this study demonstrates that treating HIV-infected partners in serodiscordant couples with ART leads to a 96% decrease in HIV acquisition by the uninfected sexual partners (El-Sadr et al. 2011:2296). Having said this, this does not mean that safe sex practices and other forms of prevention are not needed.
As Zambia and other African governments proceed into the second decade of providing ART at scale, the number of people developing resistance to first-line regimens is, as expected, growing. There are also increasing numbers of reports of patients failing second-line therapy [(Ajose et al., 2012)]. Unfortunately, the global enforcement of intellectual property protection over the last decade puts into serious question the extent to which countries like Zambia will be able to ensure access to newer regimens.

WHO recommends that countries begin to develop policies to have third-line regimens in place [(GRZ, 2010b)], but currently third-line regimens are widely patented and can cost as much as 19 times the price of first line. Consequently, most African countries make no provision for third-line therapy [(UNAIDS, 2011b)]. Once again, Zambia is an exception, and the latest ART guidelines recommend two drugs [...] for the management of patients failing second line. However, these recommendations are preceded by the sobering caveat that there are currently no third-line options available in the public sector due to the high cost of these drugs [(GRZ, 2010b)]. […]

Ten years ago the high cost of ART meant that HIV/AIDS was a disease that was either treatable or untreatable, depending on whether you lived in the Western world or in Africa. For people failing treatment, there is a risk of returning to this inequitable situation. This will only be avoided by the kind of decisive political action exemplified by Zambia back in 2002 that put the provision of life-saving ART above the intellectual property interests of pharmaceutical companies.”

Clearly a lot of work remains to be done, and as Ford (2012:461) points out, it will ask for decisive political action from numerous parties. AVERT (nd) points out that “one of the main issues hampering the scale up of treatment in Zambia is a lack of funds”.

### 1.6 Community Home Based Care Programme of the Archdiocese of Lusaka

The research conducted for this thesis was conducted through the Community Home Based Care Programme of the Archdiocese of Lusaka (CHBC).

The CHBC started in the early 1990’s as a response to the increasing numbers of PLHIV. The CHBC is a Faith Based Organisation (FBO). The CHBC has a coordination office in Lusaka and has Home Based Care (HBC) projects in 42 areas. The CHBC covers areas in Lusaka and Central province in the following districts, namely: Lusaka, Chongwe, Kafue, and Mumbwa. In the year 2008 the programme offered support to 18,500 Orphans and Vulnerable Children (OVC) and 15,575 PLHIV. This was done through 2500 care givers and 124 OVC focal persons.

Originally the CHBC’s aim was to alleviate the suffering of PLHIV in communities. The services provided by the CHBC, through its HBC projects, traditionally occurred in the clients’ homes and communities and the role of the caregivers (who were the backbone of the CHBC) traditionally was one of caring for the sick and assisting them in the last stages of their lives. Originally the structure of the CHBC was not centralised, however in 1996, due to the increasing number of PLHIV, a central Coordination Office (CO) was created. The CO is there to assist in management of the projects. In addition, it is responsible for the overall governance strategic/financial management and operational planning of all resources and services within the entire HBC programme.

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26 This chapter is largely based on a chapter describing the CHBC in a project proposal that was co-authored by the author of this thesis named: “PROJECT PROPOSAL: Sustainable Livelihoods Economic Empowerment in Zambia” and was written in 2011.

27 These figures are based on 62 projects. A new Diocese was recently created in Kabwe and the number of projects has reduced to 42.
As mentioned the CHBC consists of a number of HBC projects. The purpose of these projects is to deliver CHBC services to the service users – PLHIV, families, and communities. Each project has a specific catchment area and is run by a project coordinator who is responsible to coordinate the day-to-day operations of the project and communicate with the CO. Through the CO the project coordinator can submit applications for funding and request for supplies (including basic medical supplies, nutritional support, etc). In the past all projects also had a paid position for an OVC focal person who was responsible for the activities regarding OVCs. This is now a voluntary position and as such not all HBC projects currently have an OVC focal person. The backbones of the HBC projects are the voluntary caregivers (VC). The vast majority of the CHBC services are provided by the VC. VC’s live in the community that they work in and as such have personal knowledge of the community. VC’s visit clients in their homes and provide CHBC services there. Depending on the situation and needs of the client the VC will make home visits. They also play a role in supporting and advising family care givers how they can support their ill family member best.

Services offered by the CHBC projects include:

- Provision of basic medical and nursing care
- Support and training of family caregivers in provision of appropriate care for PLHIV
- Provision of household support (cleaning, fetching water, cooking) and supplies (food, soap, blankets)
- Provision of basic medications and medical care supplies
- Assistance with basic treatment for opportunistic infections
- Treatment and adherence monitoring of TB and ART
- Assessment and referral to further medical care as needed
- Mobile and project based Voluntary Counselling and Testing (VCT)
- Promoting and assisting the increase accessibility of ART
- Psychosocial support and educational services

The coming of ART has changed the CHBC and the role of the HBC projects. The number of bedridden patients has decreased dramatically and the role of the caregivers, and the individual projects in the programme, has as such also changed. PLHIV now have access to ART and the traditional role of caregivers is largely not needed anymore. Having said this it is important to realise that the effects of the HIV epidemic are still being felt today and the large period in which there were no ARVs available still influences the situation. Large numbers of children lost one or both parents due to HIV, many families and communities as a whole suffered socio-economically, and many people lost their partners. This has left households and even entire communities very vulnerable. The CHBC today continues to mitigate the impacts of HIV.

Many of the HBC projects continue to assist PLHIV and other chronically ill where necessary but, as mentioned, for a large part their activities have shifted. The new activities now include: making ART accessible, promoting ART adherence, making Voluntary Counselling and Testing (VCT) accessible and available, assist in improving livelihoods, provide psychosocial support, etc.

1.7 Report Set Up

This chapter has provided information about Zambia, PLHIV in Zambia, ART, and ART in Zambia. In Chapter 2 the aim of this research will be provided, then the relevant theories and literature will be discussed and a theoretical framework for the research conducted will be provided. Some concepts which are part of the aim are discussed in the chapter. This is followed by the research questions that were formulated to achieve the aim of the research.
Following the second chapter the methodology will follow in Chapter 3. The fourth chapter provides an overview of the research conducted in 2010, by the author, which forms a basis to answer part of the research aims as well as the basis for this further research. The fifth chapter provides an overview of the data that was collected. Chapter 6 looks at the changes that took place between 2010 and 2012 amongst the same households. In Chapter 7 a more in depth analysis is made into the effects of ART on individuals and their households. In particular the process of time and personal factors from both before and at the start of ART are discussed in relation to the current well-being outcomes of PLHIV on ART and their households. Following this the final data chapter, Chapter 8, will look at the diversity of situations that exist. Chapter 9 is the final chapter that contains the research conclusion and recommendations.
Chapter 2 – Aim of the Research

2.1 Introduction

In the previous chapter background information has been given on HIV and ART in general and on the situation in Zambia in particular. In this chapter a more detailed look at the effects of HIV and ART on a personal level will be taken. How are individuals and their households impacted? Following this introduction the problem statement, the research relevance, and the theory will follow. Additionally some of the important terms that will be used in this research and the research aim will be introduced. The research questions that will provide the basis to answer the research aim will also be discussed and introduced.

This research builds on research that was done by the author in 2010, and the results from 2010 provide a starting point for this research. In Chapter 4 an overview will be given of the research design, results, and conclusions of the research done in 2010. This research had as aim to uncover some of the socio-economic consequences of ART. The current research intends to gain a more comprehensive understanding of the impact of ART on individuals and their households. By taking a broader perspective than merely looking at the socio-economic consequences of HIV and ART it is hoped that a better understanding can be gained of how ART is changing and impacting people. HIV positive individuals taking ART are affected personally and can respond in numerous ways to their situation and their surroundings will both impact this and be impacted by it.

2.2 Problem Statement

HIV is having far reaching effects on all levels of the Zambian society. The effects of HIV are seen immediately when individuals start to become ill, additionally they continue to be felt long after the death of the infected individual. Barnet and Blaikie (1992:55) argue that these long-term effects make the HIV epidemic a ‘long-wave’ disaster. The effects of the HIV epidemic on livelihood outcomes are profound and varied (Masanjala, 2007:1035).

The HIV epidemic is said to be “the most serious threat to the development agenda in Zambia” and unless HIV prevention, treatment, care and support is scaled-up most Millennium Development Goals (MDGs) will not be achieved (UNAIDS, 2008a:1). Seeing that the epidemic strikes the most economically productive members of society it is not surprising that it brings with it profound social and economic consequences (Mwakalobo, n.d.:51; D’Adda et all, 2009:180). Increasingly it is becoming clear that HIV must be understood as more than just a health issue; “it has far reaching social, political, and economic implications for individuals, communities, and institutions at all levels” (Edström & Samuels, 2007:1). Similarly, Barnett & Whiteside (2002:5) tell us that the HIV epidemic is affecting not only the health of individuals but is also affecting the welfare and well-being of households, communities, and ultimately entire societies. These wide ranging effects on “different sectors of society and socio-economic dynamics of households and communities has meant that it is now perceived as a much broader development issue” (Nkurunziza & Rakodi, 2005:5).

One of the possible ways to mitigate some of the impacts of HIV is through the provision of ART. Since 2004-2005 an enormous increase in the number of people in Zambia receiving ART has been seen. In 2011 there were 385,498 people receiving ART in Zambia (GRZ, 2012:36) which is a 82% coverage of those in need of ART (UNAIDS – AIDSinfo, nd).

The effects of ART on the physical health, in medical literature, of people has been well documented elsewhere (see: Ferradini et all (2006); Ivers et al (2005); Laurent et al (2002)) with positive treatment success "with regard
to survival, physical health, and immunological responses” (Wagner et al, 2009:793). The broader effects of ART on individuals and their households, however, is far less clear and only limited research into socio-economic effects and well-being has been conducted.

Wagner et all (2009:793) suggest that “the direct effects of ART on physical health may lead not only to improved physical capacity to work and function, but also contribute to increased confidence about one’s abilities (self-efficacy), and heightened goals and expected outcomes for behaviours related to work, productivity, and being able to provide for one’s family”. Existing research (see Rutenberg & Samuels, 2008; Goldstein et al, 2005; d’Adda et al, 2009; Wagner et al 2009) is positive with regards to the possible mitigating impacts of ART. The results from the study conducted by d’Adda et al (2009) suggest that the “provision of ARV treatment generates a wide variety of benefits to households in resource-poor settings.” At the same time though Rutenberg & Samuels (2008:3) found that the majority of the people that they surveyed had experienced, due to their illness, major setbacks in their livelihoods. Research conducted suggests that ART does allow people to regain a large part of their health, quality of life, and livelihoods. However research also suggests that while people do recover a large part of their physical health it is questionable whether they will ever fully recover their lives (see Wagner et al, 2009; Reijer, 2010; Rutenberg & Samuels 2008).

It is becoming increasingly understood that households are not affected in a uniform way (Swaans et al., 2008:167). As such, “Households affected by HIV/AIDS cannot be treated as a homogeneous group” (Wiegers et al., 2006:1073). In addition, it should not be forgotten that HIV not only affects those that are infected but that “everyone experiences HIV/AIDS, regardless of ‘personal’ HIV status” (Lumka & Squire, 2009:257). Individuals, households, and communities differ and while certain coping strategies may be similar there are also considerable differences between them. Strategies adopted by individuals and their households not only have an immediate effect but often will have long lasting consequences.

Clearly it is important to have a comprehensive understanding of the effects of ART on HIV positive individuals and their households. Is the perception of HIV within communities and society at large changing? How does HIV impact the well-being of individuals, and is this changing with ART? Are strategies that people put into place when household members fall ill changing? And, if so, how are these impacting individuals and their households? In order to answer these questions the following research aim was formulated:

To provide an insight into the impact of ART on the well-being of HIV positive individuals and their households in Lusaka, Zambia.

2.3 Research Relevance

Livelihood research on the impact of HIV has systematically shown that “the impact may strip individuals, households and communities of all of their assets” (Swaans, 2008:167) and that households may hardly cope or not cope at all (Rugalema, 2000:543). The coming of ART may be changing the strategies deployed by individuals and their households and is seen as one of the ways of mitigating the impact of ART. While certain (coping) strategies that are adopted by individuals and households may appear to be similar it is important to realise that different individuals and households are not affected in a uniform way and as such there will be a difference in impact and response. Understanding these differences is of vital importance in gaining a better understanding of the potential and limitations of ART. A comprehensive understanding of the impact of ART on individuals and their households may provide a starting point for other research and policy implementations in projects to further assist and support PLHIV and their households.
Research has shown that while the physical well-being of HIV positive individuals is largely regained through ART the livelihoods of people appear to be lagging behind (see Rutenberg & Samuels, 2008; Goldstein et al, 2005; d’Adda et al, 2009; Reijer, 2010). To better understand why certain individuals and households fare better than others it is important to gain both a better understanding of what aspects of their livelihoods are lagging behind as well as what decisions people are taking. This research may provide an insight into which aspects of people’s well-being is improving by looking at and understanding the diversity and impact of responses. The physical well-being, at the time of the initiation of ART, might be another factor determining the well-being of people after a specific period of time. CD4 counts may well be an indicator for physical well-being, in which it is expected that the well-being of people with a CD4 count below 100 cells per microliter of blood is expected to be much lower than that of someone with a CD4 count of 300 and similarly there physical well-being is expected to be lower than that of someone with a CD4 count of 500. With ART CD4 counts improve over time, however medical research has shown that only 56% of the people who start with ART when their CD4 count is already very low (<100 CD4 cells per microliter) regain a good immunity (>500 CD4 cells per microliter).

2.4 Theory

2.4.1 Introduction
Over the years a lot of HIV related research has been done and a vast collection of literature exists on the subject. However, a large part of this literature stems from a time when ART was not freely available in large parts of the world. Currently more and more research is being conducted on HIV in relation to ART. This is not to say that the research conducted prior to the coming of ART is no longer relevant. On the contrary, it remains, even today, invaluable and highly relevant to current research. Some of the impacts of HIV may be mitigated through ART, however this will depend on when people start with ART and how they react and respond to ART. Often people still go through some period of illness; this may be before the start of ART as well as after the start of ART. As such, the household may still face similar situations as prior to ART, however, these will often be shorter and do not ultimately result in death as was the case before ART. As such coping strategies may still be put in place.

2.4.2 HIV before the introduction of ART
Numerous studies have been conducted on the impact of HIV (in a time prior to ART being widely available) on people, households, and communities. HIV impacts people, households, and communities in different ways and at different times. Drimie (2003:648) argues that in order to fully understand the impacts over time it is important to look at “the phases of HIV/AIDS: asymptomatic; early illness; chronic illness; critical illness; death and, lastly, survivors” and that “each phase of the disease is associated with a different impact”.  

28 CD4 cells can be described as the managers of the immune system. CD4 cells are in fact several different cells, like in the management of an organisation. The variety of the cells enables the immune system to react to all kind of threats. The number of CD4 cells per cubic microliter varies from 500-600 to 1,000-1,200 in a healthy person. The number of CD4 cells per cubic microliter varies during the day and variations of up to 40% within 24 hours are possible. For a more thorough explanation about CD4 cells and CD4 counts please see “Text Box 7.1: CD4 cells and CD4 count – What it is and how it works” in Chapter 7 in Section “7.2 Starting with ART”

29 From this point forward all CD4 counts mentioned will be in “cells per microliter of blood”

30 Antiretroviral Therapy (ART) aims at blocking the replication of HIV and prevents as a consequence the further destruction of CD4 cells. After a few weeks of ART the concentration of HIV drops and slowly the CD4 count increases. However, the later in the disease progression ART starts, the less likely it is that a full recovery is made. For a more thorough explanation about ART and CD4 counts please see “Text Box 7.1: ART and CD4 count” in Chapter 7 in Section “7.2 Starting with ART”
A useful tool that was developed before the introduction of ART can be used for the further conceptualisation of HIV impacts (prior to ART) on households. This is depicted in the diagram below:

**Figure 2.1: The effects of HIV related income shocks and safety nets on household economies**

When looking at the impacts of the epidemic on household welfare we find that the nature of the epidemic translates into long periods of lower incomes and higher expenditures. First, in the early stages a household member may suffer from unspecified conditions, such as weight loss, skin conditions, diarrhoea, and fever. Over time the situation becomes more serious and people may fall ill more frequently and be more exposed to opportunistic infections (clinical stage 3). As the person becomes more and more sickly the number of hospital visits starts to increase, and at the same time so do the household expenditures. But already during the first stages household expenditure may have increased; households may attempt to find remedies for the unspecified conditions that the sick household member is suffering from. While the household member is sick he/she is increasingly unable, or completely unable once bedridden, to work and contribute to the household’s labour force. Simultaneously the person also needs to be cared for, meaning that other household members are also not available to work. While production decreases so does income, yet at the same time the expenditures that need to be made to care for the HIV positive individual increases. These impacted households generally appear to adjust to this situation through typical coping mechanisms\(^{31}\), including saving reductions, asset sales, labour supply adjustments, and schooling investment (D’Adda et al, 2009: 181). D’Adda et al (2009:181) tells us that the “behavioural change needed to cope […] is long lasting: income remains lower even after the sick person’s death and household members’ coping strategies are retained in the medium term”.

While households are facing an increase in costs and dealing with a decrease in labour and income a number of strategies will be deployed. Individuals and households, when impacted with adult illness and death, will undergo processes of experimentation and adaptation whilst attempting to cope with the situation (UNAIDS, 1999:17).

\(^{31}\) Typical coping mechanism in settings where credit and insurance markets are lacking.
UNAIDS (1999:17) identifies a number of household coping strategies:

<table>
<thead>
<tr>
<th>Strategies aimed at improving food security</th>
<th>Strategies aimed at raising and supplementing income so as to maintain household expenditure patterns</th>
<th>Strategies aimed at alleviating the loss of labour</th>
</tr>
</thead>
</table>
| • Substitute cheaper commodities (e.g. porridge instead of bread)  
• Reduce consumption of the item  
• Send children away to live with relatives  
• Replace food item with indigenous/wild vegetable  
• Beg | • Income diversification  
• Migrate in search of new job  
• Loans  
• Sale of assets  
• Use of savings or investments | • Intra-household labour reallocation and withdrawing of children from school  
• Put in extra hours  
• Hire labour and draught power  
• Decreasing area cultivated  
• Relatives come to help  
• Diversify source of income |

Table 2.1: Typical coping strategies of household who are faced with affected by HIV

A household’s ability to secure its immediate well-being and adjust to future shocks may be severely hampered by the impact of HIV. Illness can be seen as a severe shock on the household.

The livelihoods framework is a useful tool to better understand the coping strategies mentioned above. The sustainable livelihoods framework is an analytical framework that was developed in the 1990’s. While it was initially developed in relation to rural development it is now increasingly being applied to urban situations (see Rakodi, 2002). Chambers and Conway (1991:6), two of the key thinkers of the sustainable livelihood approach, state that a livelihood comprises of: “the capabilities, assets (stores, resources, claims and access) and activities required for a means of living: a livelihood is sustainable which can cope with and recover from stress and shocks, maintain or enhance its capabilities and assets, and provide sustainable livelihood opportunities for the next generation; and which contributes net benefits to other livelihoods at the local and global levels in the long and short term.” The framework is premised upon a few key principles. It acknowledges that poverty is not only a lack of wealth but rather a condition of insecurity. Additionally, poverty is not seen as something that is stable, permanent, or static. The framework is people centred and takes, rather than deprivation, the ‘wealth of the poor’ (Nkurunziza & Rakodi, 2005:7) as starting point.

The main components of the livelihoods framework are: the livelihoods assets, transforming structures and processes, and livelihood strategies and outcomes. The assets pentagon is the core of the framework. Its main components comprise of five forms of capital: Human capital, Natural Capital, Financial Capital, Social Capital and Physical Capital. These asset categories can be deployed by households in their livelihood strategies. Stokes (2003) explains that utilizing “these assets, households adjust to their physical, social, economic and political environments through a set of livelihood strategies designed to strengthen their well-being”.

Potter et al (2008:485-486) describe the capitals of the ‘asset pentagon’ as follows:

1. **Human Capital**: the skills, knowledge, ability to work and good health. It is both a means of achieving livelihood outcomes and an end in itself; overcoming a lack of education, for example, can be a primary livelihood objective.

2. **Social Capital**: [...] the social resources (networks, membership of groups, relations of trust, access to wider institutions of society) upon which people draw in pursuit of their livelihood objectives. Social resources may be enhanced through networks that increase people’s ability to work together and to access wider institutions such as political or civic bodies. Relationships of trust and exchange also provide the basis for many informal safety nets among the poor.
3. **Natural Capital**: the natural resource stocks from which resource flows and services useful for livelihoods are derived. These may include assets used directly in production, such as land or trees, and less tangible public goods such as biodiversity or the atmosphere.

4. **Physical Capital**: the basic infrastructure and producer goods needed to enable people to meet their basic needs and function more productively. These typically include secure shelter, affordable energy, adequate water and sanitation and access to transport and information.

5. **Financial Capital**: the financial resources that are available to people (savings, credit, remittances or pensions) that provide different livelihood options.

The livelihood pentagon can be depicted as follows:

![Figure 2.2: Livelihood pentagon](image)

The model can be used to see how these forms of assets can be used as a means to understand what forms of strategies people may deploy and what structures and processes surround and impact this. Using the livelihoods approach it can be seen that one of the first things that HIV impacts is the human resources of a household. When individuals start becoming increasingly ill their productivity declines as a result of illnesses, stress, depression and the eventual death. A further stress is placed on the household’s human resources when the sick household member is in need of care thus causing a further decline in the household labour availability. The much needed care that the ill household member needs may divert other household members from working and children from going to school. In the context of HIV this stress on human resources is particularly apparent seeing that HIV is most prevalent amongst the productive members of society.

The loss of human capital impacts the other household resources. It is argued that the loss of human resources particularly affects the financial resources of the household. Financial resources, such as savings and any access that households may have to credit, are depleted when the loss of human resources translates to financial shortfalls. As household labour productivity decreases when a household member becomes sick and further decreases when other family members need to care for this family member the various income sources decline or disappear. In addition the costs related to various treatments for opportunistic infections that the sick family member is prone to further strains the financial resources of the household. When families become increasingly desperate they may also spend additional money on alternative treatment options when they feel the regular health care system is not working. Particularly before ART became available, families may have looked for cures outside the regular health care system. Visiting traditional healers is not only potentially dangerous for the health of the sick family member but in addition is very costly. Finally, sick household members, before ART became available, inevitable passed away. The household at this point is not only left with the grief of having lost a loved

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32 Until this point the terms asset and capital have been used in relation to the livelihoods assets pentagon, in the diagram it can be seen that the term resources is used. From this point forward the term resource will be used rather than asset or capital. For the discussion on the differences between capitals, assets, and resources as well as an explanation as to why the term resources is used please see section 2.4.4.
one, but also with the resulting permanent loss of human resources and the additional financial losses with regard to burial expenses. During the period that the family member is sick, households are unable to save, existing savings are depleted, and finally households may borrow money leaving them in debt.

Following the depletion of the human and financial resources the household’s natural resources are affected. Natural resources, such as land, are often sold off, or rented out if possible, when household no longer have any financial resources available to compensate for the loss of human resources. Particularly in rural areas the selling off of land may have detrimental effects on households; often households depend on this land for their livelihoods. In urban areas far less people are dependent on natural or environmental resources for their livelihoods making this arguable less appropriate in urban contexts. There are of course exceptions to this; households may for example engage in urban agriculture or even own and cultivate land in rural areas while living in an urban area.

A number of authors have argued that in the urban context, where the research for this thesis was conducted, it appears that security is crucial to households (Beall, 2002; Rakodi, 2002; Wood, 2003; Nkurunziza & Radoki, 2005). In the urban context certain physical resources may play a similar role to that of natural resources in rural areas. For urban households their housing is “often one if their most important assets […] as it is used for both productive (renting rooms, using the space as a workshop area, and reproductive purposes in addition to shelter” (Rakodi, 2002:47). Moser (1998:10) argues that the importance of housing (the house and its plot) as a productive asset for the urban poor can be viewed in a similar way as land is seen in rural areas.

Physical resources comprises of basic infrastructure, such as housing, production equipment, tools and livestock. Housing, as discussed above, has a variety of purposes. These physical resources can be used by the household to maintain or enhance their well-being. Often these physical resources are closely related to the income generating activities of households. When the household productivity decreases so does their ability to maintain their physical assets; necessary house maintenance may not be done and repairs on equipment may be postponed. Additionally, physical assets may be sold as a means to cope with the financial demands of caring and treating for ill family members. When maintenance work is not carried out this may also impact the value of this resource; households may not be able to rent out part of their house or rent out faulty machines. Additionally when physical resources are sold they are not available, after the death of the household member, when people can return to work.

Social capital is often also reduced; social stigma plays a large role in this depletion of social capital. People may be scared of interacting with families that are affected by HIV for fear of contracting the disease themselves. This can lead to the crippling of social structures and leads to increased social exclusion. Such social exclusion is not only emotionally crippling but also affects the opportunities for support that households have – further straining their financial resources. Additionally traditional coping mechanisms and safety nets within communities and families are becoming overburdened. This further increases the vulnerability of those affected, afflicted, and infected by HIV. White and Robinson (2000:21) explain that “given the systematic nature of HIV/AIDS and its correlation within families and communities, social capital may become severely straining over the long term”.

Within the livelihoods framework it can be seen that households can put into place certain coping strategies and react in a number of ways to possible threats (see, for example, household coping strategies as presented previously). These strategies can be referred to as “risk management strategies and can be classified as either ex-ante (pre-crisis) risk mitigation or preventative measures, or ex-post coping or adaptive strategies (invoked after the event) (Devereux, 2001)” (Nkurunziza & Radoki, 2005:15). Ex-ante refers to strategies that can be seen as either preventive or mitigating, in which the former is often aimed at reducing the probability of a negative outcome occurring. Instead, the latter is aimed at dealing with the external shock that has hit, for example by attempting to lessen the income reduction by diversifying income (ibid). Ex-ante strategies, for example creating
savings or getting insurance, are considered to be deliberate and planned while ex-post are considered as ad hoc and reactive. Having said this, while ex-ante strategies at first hand appear to be effective on the short term, on the long term they are often economically crippling\(^{33}\). Ex-post strategies are often seen as coping or adaptive strategies (ibid) – and in the past these were often the only strategies that poor families impacted by HIV had at hand. The costs of putting such mechanisms in place might in the short term help the household but on the long term will impact the household negatively.

Urban households are “subject to both long-term stresses and periodic internal and external shocks” (Nkurunziza & Radoki, 2005:16). Certain households may have stronger safety nets and as such may also recover quicker from stresses and shocks. Households and families with a high prevalence of HIV will face more losses in human capital. At the same time the amount and diversity of resources that households may have available will also impact to what extent the household needs to put certain coping mechanisms in place.

2.4.3 HIV after the introduction of ART
With the coming of ART the above scenario has in part changed. When people fall ill now, or preferably even before they fall ill, they may be able to start ART and the previously inevitable outcome of death may be avoided. However, people may still delay with starting ART or may suffer from side effects. This may result in households having to resort to putting coping strategies in place. In addition, while people may recover their physical health through ART it should not be forgotten that people are still HIV positive. The above described scenario and particularly the coping strategies may as such still be used today.

Earlier the effects of HIV related income shocks and safety nets on household economies was depicted (see figure 2.1). In the figure 2.3 the earlier diagram (figure 2.1) has been adjusted to illustrate how ART may influence the above sketched scenario and also show how the different starting points may influence livelihood outcomes.

![Possible effects of ART on the effects of HIV on household economies](image)

*Figure 2.3: The possible effect of ART the effects of HIV related income shocks and safety nets on household economies*

\(^{33}\) “Ex-ante risk management strategies [...] are often economically inefficient, as there is a tendency for households and individuals to choose lower but less variable yields over yield maximisation, given the fact that variability is a crucial determinant of vulnerability (Devereux, 2001; Wood, 2003)” (Nkurunziza & Radoki, 2005:15).
In the above diagram it can be seen how ART may affect the impacts of HIV on households, seen earlier. The outcome still varies considerably, for some individuals and their households the original pattern can still be seen, but for others a far more positive outcome can be expected. For individuals who start ART some of the consequences of HIV related income shocks may be avoided. The degree to which these can be avoided will depend on a number of factors: when the individual starts with ART, how he/she responds to the medication, original safety net, and socio-economic status of the household, etc.

Research conducted by the author in 2010 suggests that:

“[..] When people become ill, the situation for both the patient and for his or her household slowly deteriorates. Many people and their households literally hit rock bottom. As a result of illness and its impacts for households jobs are lost, assets are sold, family is called in to assist, and the health of the person who is ill is often so diminished that they are bedridden. It is at this point that they start to receive ART. If the medication works, the health of the sick person slowly starts to improve. The road to recovery for the patients and their households is a long one.

The data shows that people who start ART begin a long recovery process. Their health improves as does the socio-economic situation of their households. The data indicates that after 2 to 3 years on ART substantial improvements are visible both in terms of the patient’s health as well as the economic well-being of the households. [...] After 4 to 6 years on ART we see even more improvement and at a first glance it may appear that people have regained their previous health and socio-economic status. [...] For example, the data reveals that after 4 to 6 years of ART households have managed to regain their sources of income. While this is true, the data also shows that while people may have found a new job, their salaries are much lower.

Recovering from shocks [...] takes many years and we need to consider that the patients and these households will never fully recover. Especially in the beginning, when a person has just started ART, the recovery takes place quickly. The patients regain part of their health status, they no longer need support and they may be able to return to work. As a result, the strain on households is reduced, productivity increases and the socio-economic status of the households begins to improve. [...] After the relatively quick recovery in the earlier stages a much slower recovery is seen in the following years. People have lost their jobs as a result of illness and have difficulties securing new work. Also, quite a number of patients reported that their physical strength is not as good as it was prior to their illness. Additionally households cannot recover from some of the impacts they experienced such as the sale of irreplaceable assets or the loss of household members. (Reijer, 2010:32-33)

Both in developing and developed countries studies have shown that treatment reduces morbidity and mortality among HIV-infected people (for developing countries see Laurent et al, 2002; Marins et al, 2003:1680; Koenig et al, 2004; Wools-Kaloustian et al, 2006). Various studies have shown that ART can prolong life and improve the health of HIV-infected individuals. Coetzee et al (2004:887) write, already in 2004, in a paper presenting the outcomes of two years of ART provision in South Africa that “the benefits of antiretroviral therapy (ART) at an individual level are incontrovertible.”

A number of studies have been conducted at household level on the impacts of ART. Some of these have focused specifically at livelihoods (see Rutenberg & Samuels, 2008) whilst others have focused more on socio-economic impacts (see Goldstein et al, 2005; d’Adda et al, 2009). The results from the study conducted by d’Adda et al (2009) suggest that the “provision of ARV treatment generates a wide variety of benefits to households in poor resource settings.” Their research examines the impact of ART on the time allocated to various household tasks by HIV infected individuals and their households. They find that after initiation of the treatment the household members of the HIV-infected adult will spend less time caring for the sick family member
and seeking health care. Moreover, they found a decline in the time spent by children on non-market activities, an increase in school attendance, and an increase in time spent on income generating activities.

Whilst an increase in labour supply and reallocation of household tasks may provide significant benefits it should not be forgotten that many of the coping strategies people have put in place before the initiation of the ARV therapy may prove difficult to reverse or may even be irreversible. Rutenberg & Samuels (2008:3) found that the majority of the people that they surveyed had experienced, due to their illness, major setbacks in their livelihoods. Now that they have started ART their health has bounced back, however their livelihoods still lag behind. Rutenberg and Samuels (2008:3) explain that for most people they interviewed their livelihoods has slipped from "relatively high return livelihoods, to those with low returns" and that this was a result of their illness. Indeed illness often has “meant the loss of jobs, the sale of assets, the collapse of traditional safety nets and falls in standard of living and quality of life” (Rutenberg & Samuels, 2008:3).

2.4.4 Towards a more holistic understanding of HIV with ART

While the effects of ART on socio-economic level and well-being remain understudied it is believed that the treatment has the “potential to have beneficial effects on work and productivity, and preservation of assets and resources” (Wagner et al, 2009:793). Wagner et al (2009:793) further suggest that “Social cognitive theory suggests that the direct effects of ART on physical health may lead not only to improved physical capacity to work and function, but also contribute to increased confidence about one’s abilities (self-efficacy), and heightened goals and expected outcomes for behaviours related to work, productivity, and being able to provide for one’s family - all of which can contribute to behaviours that improve economic well-being” (emphasis added). In order to move away from more restrictive socio-economic approaches of studying the impacts of HIV and ART on PLHIV the term well-being will be introduced. White & Ellison (2006:4) say the following about well-being: “Building on established critiques of narrowly [defined] economic approaches to poverty or development and restrictively medical understandings of health, wellbeing offers a rounded, positive focus which includes not only material resources and social relationships, but also the psychological states and subjective perceptions of people themselves.”

McGregor (2006:2) defines well-being in three parts, namely: “an interplay between the resources that a person is able to command; what they are able to achieve with those resources; and the meanings that frame these and that drive their aspirations and strategies.” When combining this with the livelihoods profile it becomes apparent that simply looking at capitals will not allow us to get a full understanding of a person’s well-being.

Within the livelihoods framework the idea of different capital categories within the livelihoods pentagon was introduced. Rather than using capitals it is argued here that we should focus on resources. White and Ellison (2006) explore the ways in which the concept of resources can contribute to the understanding of well-being. Their major argument is that “resources do not have a fixed meaning but are constituted through social practice” (White & Ellison, 2006:2). Furthermore they argue that:

“While we may construct ‘resource profiles’ to record different types of resources, their significance for wellbeing will depend on understandings about how these resources can and cannot be used in particular contexts. We must avoid reifying categories like ‘capitals’ or ‘assets’. All forms of resources, such as land for example, have material, relational and symbolic dimensions. How resources are used in practice also depends critically on who is involved, and the structural forms of power they can deploy. This approach exposes the common ‘conceit’ when development agencies assume that because they are familiar with a resource they understand what would constitute its ‘rational’ use in different contexts”. (White & Ellison, 2006:2)
This in turn asks that a closer look is taken at the terms Capitals, Assets, and Resources (CARs). In a paper published in Progress in Development Studies, van Dijk (2011) develops a critical realist livelihoods approach. In this paper she discusses “the problems with the present use of capitals, assets, and resources (CARs)”. Van Dijk (2011:107) provides working definitions for the above mentioned terms and explores the issues that should be taken into consideration when qualifying them. Capitals are “something of value to one’s livelihood which is ownable, able to be deployed in such a manner that it accumulates more of itself or something else of value – thus it must be convertible as well” (ibid). An asset can be defined as “something of value that is ownable (car, skills) or claimable (entitlements, friendship) where value commonly implies economic value towards one’s living, but which also refers to things that have intrinsic value exclusively or in addition to dollar value” (ibid). And finally, resources “are something that can be used towards completing a task or obligation, solving a problem or achieving a goal” (ibid). Using the above definitions it becomes apparent that ‘resources’ is the least economic term of the three and additionally does not require ownership (ibid). While the other two terms require ownership resources can also refer to things that a person has access to, thus broadening the scope considerably. Van Dijk (2011:107) explains that resources require a sense of access, awareness and intention; “in order for a resource to be of use, someone must be aware of its existence; perceive it as useful; and be able and willing to access it”. Van Dijk (2011:107) further argues that the following issues should be taken into consideration when referring to or using these terms:

- Capital ≠ resources or assets.
- Assets can also be considered resources but not all resources are assets. They [assets] can only become capital if they can be converted (in form or function) and invested (transferable) in a manner that allows for accumulation.
- Resources can encompass both one’s capital and assets but also refers to tangible and intangible things of use or help that one does not own but has knowledge of and access to."

Van Dijk (2011:107) points out that it is problematic to use these terms interchangeably without appropriate qualification or theorisation. The example that is given by van Dijk encompasses education which if it is of use to a person is a resource however “whether or not it can be deployed in a particular labour market (transferable) and lead to income (convertible), or increased income beyond what is needed for expenses (accumulation), cannot be assumed” (Dijk, van., 2011:107).

Considering the above definitions for CARs it is problematic to look at solely assets or capitals in the livelihood pentagon. In section 2.4.2 the ‘assets pentagon’ was discussed. Human capital was there explained to incorporate: “the skills, knowledge, ability to work and good health. It is both a means of achieving livelihood outcomes and an end in itself; overcoming a lack of education, for example, can be a primary livelihood objective” (Potter et al., 2008:485). The livelihoods pentagon used in this research will look at resources. Looking at the previous example regarding education it can be seen that simply quantifying a certain level of education as a capital may not always represent reality. The level of education of, for example, a secondary school teacher who has become ill and is therefore unable to work is at this time still a resource however should be considered a capital. The education that this individual has still exists and may still even prove useful for the household, however at this time the individual cannot deploy this skill on the labour market and turn it into income. In addition, when the individual regains his/her strength after starting with ART there is no guarantee if he/she can still deploy this skill to the labour market in the same way and turn this into the same income he/she had before. Having recovered from illness the individual, who previously was employed as a secondary school teacher, may find that his/her position has been filled and no comparable jobs are available.

Resources as such add a sense of agency (the ability to act: discussed more thoroughly later on in this section) to the livelihoods pentagon and “points to an active relationship between householders, the material and other assets to which they have access, and the strategies which they use to deploy them” (White & Ellison, 2006:9).
Human behaviour and development has a profound impact on well-being. In order to gain a better understanding of how human beings may develop and behave in different ways it is important to see the broader environment that people are part of. Bronfenbrenner (1979:21) in this regard stated that understanding human behaviour “requires examination of multi-person systems of interaction not limited to a single setting and must take into account aspects of the environment beyond the immediate situation containing the subject”.

The Ecological Systems Theory, introduced by Bronfenbrenner, allows us to assess an individual in the manner, mentioned above.

Ecological Systems Theory allows for the examination of an individual both within its environment and as influenced by the interconnections of systems (Burch-Fleming, 2008:10). Rothery (2001) argues that this theory encourages a more holistic view of the individual while at the same time taking into consideration and including individuals, families, communities, and other systems that may be important to, or influence, the individual’s needs. The Ecological Systems Theory consists of a number of systems of which an individual may be part of, these include: Microsystem (the setting in which a person lives, and may include: family, school, church, peers, health services, etc); Mesosystem (the interaction and relationship between the Microsystems); Exosystem (here the settings have direct influence on the individual while the individual has no active role in determining the settings, for example: social services, media, industry, politics); Macrosystem (here the ideology or culture in society influences the individual); Chronosystem (this is a result of a person’s experience in life, including environmental events and transitions in an individual’s life which includes the history of an individual).

Research in geography has until now not incorporated Ecological Systems Theory. Nevertheless, it might be useful to explore geography within this theory. The Microsystem is the setting in which a person lives; a setting here might refer to the everyday life experiences of ordinary activities and practices (see Anderson & Harrison 2010). In other words, Microsystems are the everyday reality of human beings: everyday interactions take place with family members, community members, peers, health services, etc. These Microsystems do not exist independently, but the interactions and interconnectedness of those systems (the Mesosystem) all make up a holistic view of the lives of human beings. As such the Mesosystem cannot be considered as a different (or higher) scale level but as the confirmation that the human being ‘lives in (relation to) contexts’ (Crouch 2001: 59). Important in here is that the human individual has the potential to act upon the context, but still has its main mode of experience in the everyday Microsystems someone becomes involved in. As argued by Crouch (2001: 71) “spaces, contexts and representations are embodied in practice, through which people construct their
spatialities”. He hastens to say, however, that the embodied, basic, sensory experience is formed by the everyday activities someone undertakes.

The Exosystem and Macrosystem have an influence on someone’s everyday life experiences; however, the strength of the relations between the individual and these Systems is lower. As such, this exploration into the geography of Ecological Systems Theory provides a preliminary conclusion that these systems, although important, do not form the basic mode of experience. Of course, this thesis does not want to render the Exosystem and Macrosystem as taken-for-granted; but as this research wants to provide an insight in the impact of ART on the wellbeing of HIV positive individuals and their households in Lusaka, Zambia, the main focus is upon the Microsystems and Mesosystem within someone’s everyday life.

Returning to the concept of well-being it is important to note that it is not a static concept, “wellbeing is not understood simply as a state that people do or do not experience. Rather, like subjectivity itself, it is a process, realised through the ‘work’ people put into making meaning out of their lives” (White, 2006:9). Similarly McGregor (2008:3-4) says “wellbeing cannot be thought of only as an outcome, but as a state of being that arises from the dynamic interplay of outcomes and processes. This interplay of outcomes and processes must be understood as firmly located in society and shaped by social, economic, political, cultural, and psychological processes.” The Chronosystem in the Ecological Systems model can be linked to this. White (2008:10) states that “Understandings of what wellbeing is change with historical time. People’s ideas of their own wellbeing – and their estimations of whether they have or will achieve(d) it – also change through the life-cycle. Expectations of the future and reflections on the past also have a bearing on how people conceive of their present – and how people feel about their present affects how they read their pasts and future”. Similarly the Chronosystem comprises, as mentioned previously, the result of a person’s experience in life, including environmental events and transitions in an individual’s life which includes the history of an individual. When looking at the well-being of PLHIV on ART it is important to take into consideration their personal histories and their experiences. As White mentioned expectations are linked to the past, present, and future. Discovering that you are HIV positive can, and most likely will, have a major impact on a person. In a sense people at this point will start a process of transition. One of the transitions that a person can go through is that of ‘living positively’ in which people focus on their new life one in which they are living with HIV, rather than focusing on the negative – what they lost when they became HIV positive (Tsarenko & Polonsky, 2010:465).

Both from the Livelihoods Framework and the Ecological Systems Theory a vastness of different layers and sources that can impact human beings can be seen. When looking at PLHIV who are taking ART it is important to take all of these factors into consideration. However, most of the things that have been discussed are external influences whilst the individual themselves also play a major role. In addition, using resources within the livelihoods pentagon it has been argued that agency plays a key role in this. Swaans et al (2009:168) argue that in order to understand “the underlying factors and mechanisms that contribute to or mitigate the impact of HIV [...] We have to understand people’s actions – from how they make sense of the world around them and how they deal with it emotionally, to what extent they are enabled or kept away from using resources”. In order to focus on the internal influences and agency of individuals an Ecological model of human health will be used. Ecological models of human health have “described individual health as an interconnected experience of the body, mind and spirit, nested in a hierarchy of ecosystem levels” (Swaans et al., 2009:168). This may provide a starting point to better understand people’s choices and the diversity in their responses (see van Leeuwen et al, 1999; Hancock 1993 for a more thorough discussion on ecological models of human health). Swaans et al (2009) argue that “people’s agency (the ability to act) depends on the relation between physical properties (the body), perceptions/beliefs (the mind), and emotions/aspirations (the spirit)” and that “similar connections can be defined among physical, intellectual and spiritual health at the household and community level”. This research will
incorporate part of the ecological models of health, as described above, namely: the body, mind and spirit. This is depicted in the next figure:

![Figure 2.5: Ecological model of human health](image)

Individuals who are infected with HIV will need to, in their own way, make sense of this and learn to live with this new reality. How individuals respond and deal with this information may be very different. In addition, individuals all face different circumstances, such as: physical health may become compromised, medication may give side effects, family and community members may respond to them in differing ways, self-stigma may occur, etc. An individual’s physical health (the body) may hamper, for example, the productivity of an individual and as such influence the households’ human resources. Emotionally (the spirit) individuals may react differently to learning that they are HIV positive. Swaans et al. (2009:172) describe how “dealing with the ‘message’ of HIV infection usually has a severe impact on the emotional wellbeing of the individual and the family. Emotions such as denial, fear and hope converge with this disease”. People who are emotionally distressed may in turn also be less productive and this has an effect on the human resources of the households. Feelings of denial and fear may also hamper individuals in their social interactions; this may in turn lead to a diminishing of their social resources.

Being hopeful and having aspirations for the future, such as having children or seeing your children grow up, may positively impact individuals and their households. The perceptions/beliefs (the mind) of individuals may provide a better understanding of how they cope with being HIV infected. Swaans et al. (2009:171) explains how people may make sense and take differing actions dependant on their beliefs: “if people believe that they have been bewitched, they know what kind of traditional treatment to seek; if they think an illness is the will of God, they beg for forgiveness and support or else they accept it; and biomedical information can also affect the way people deal with it”. What beliefs and perceptions an individual holds, for example regarding HIV, can impact how they deal with this. Believing that, for example, “only God can cure you” can impact an individual’s health seeking behaviour and adherence. This in turn can affect a person’s physical and emotional well-being which may then impact their and their household’s resources. At the same time having a shared belief, for example being HIV positive, that this is ‘God’s will’ can also bring support networks closer to individuals closer.

The above provides an insight into how the mind, body, and spirit can be useful within the context of researching the impacts of HIV. Not only does this provide some insight into how the mind, body, and spirit relate and influence each other but also how this may impact the different resources mentioned earlier. Having a low physical health (the body) may cause emotional distress (the mind) which in turn may affect the productivity (human resources) of an individual and a loss of human resources may then affect the other resources. The mind, body, and spirit of an individual are impacted by the environment of the individual while at the same time it also impacts the environment of the individual.

As the elaboration on Ecological Systems Theory already shows, this theory provides a better understanding of the interconnectedness of the individual and the systems surrounding him/her. Within for example the

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34 For a practical application of the ecological model of health in relation to HIV see also Nicolas & Schilder, 1997.
microsystem the individual is part of, for example, a household, a family, a school, a church, etc. When an individual discovers he/she is HIV positive this may also impact other spheres of the individual's life while at the same time these same microsystems may also impact the individual. Families may prove to be an excellent care and support network and positively influence the individual emotionally. However, the opposite is also possible whereby great stress is placed on marriages and lead to increased emotional distress. Similarly, individuals can find strength, counselling, and even support groups through their church but here too the opposite is possible. At the same time specific beliefs may even deter people from going to, for example, church or other microsystems.

The three above mentioned models, namely: The ecological systems theory, the livelihoods pentagon and the ecological model of health, can be put into one framework as a means of studying well-being. This is visualised in figure 2.6.

![Combining three models](image)

*Figure 2.6: Combining the Ecological Systems Theory, Livelihoods Pentagon, and part of the Ecological Model of Health*

In the next section some of the terminology that is used in this research is further elaborated on. In addition an operationalisation will be provided. And the research questions will be introduced.

### 2.5 Terminology

In this paragraph, some of the key terms used in this research will be discussed. The following terms will be discussed:

- Three phases: before illness, during illness, 'after' illness
- Well-being
- Insight & Impact
2.5.1 Three phases

In order to investigate the impacts of ART on the well-being of HIV positive individuals and their households it is important to gather information about three phases of the HIV positive individuals live, namely: before illness, during illness, ‘after’ illness.

As mentioned previously people, go through a transition once they discover their HIV status. A similar assumption is made here with reference to the progression of a disease. For example, consider a person who is diagnosed with cancer: after diagnosis this person then might start with chemotherapy, but often before the discovery the person may have already experienced some form of ill health, which may have led to the discovery of the disease. In a sense this person had a life before cancer, later a life with cancer, and hopefully one day a life after cancer. There is a period before illness, a period during illness, and a period after illness.

A similar logic can be applied to HIV. As such it is assumed that people will remember their life in these three stages. The three phases have been defined as follows:

- **Before illness**: This refers to the period of your life in which you were NOT suffering from any illnesses or falling ill frequently (at least not that with hindsight can be attributed to HIV infection).
- **During illness**: This is the time that the individual was ill (start ART). It is assumed that the point in time when the person first starts with ART their health will be at its lowest, hence this during illness refers to the time when you started with ART.
- **After illness**: This refers to your current situation (taking ART for a minimum of 12 months).

The stage before illness is probably the most difficult to define and for people to grasp considering it can be interpreted in different ways. It is hoped that most people will understand and that this period refers to the time in their lives when they were not ill or suffering frequently from opportunistic infections or other HIV/related conditions. The other two phases are in a sense a lot easier to define and for people to grasp. As mentioned previously it is assumed that the day that people start taking ART their physical health will be at its lowest point. There are of course exceptions and this will not hold true for everyone, but it will hold true for most people and during the selection process and later during the data cleaning period special attention will be paid to this point. The last phase refers to the current situation, as such people will be asked to reflect about their lives and well-being as it is today.

After the initiation of ART it may take a period for people to recover; a person may need time to recover their physical health after initiation, a period to adjust to the medication during which they may suffer from side effects, and finally households may need a period of time before things go “back to normal”. In order to be able to look at the impact of ART it is important to allow for this recovery to first take place. Only after recovery does it become relevant to compare people’s current situation to the period when they started ART and before they were ill. The people taking part in this research will have been taking ART for a minimum of 12 months and additionally they have to be 18 years or older. This time frame was chosen because, as explained previously, people will need some time to recover after having started ART. Additionally, the age restrictions have been put into place as this study focuses on adults and not children.

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35 It should be noted that by taking ART people are not cured of HIV and will continue to remain HIV positive for the remainder of their lives, as such “after illness” is not completely accurate. It is however a period of people’s life that is often seen as a second chance and/or a continuation of life. People no longer suffer from frequent illnesses and to a large part can live their lives in much the same way as before they became ill. This third phase of people’s lives has been defined above as the current situation of an individual who has been on ART for a minimum of 12 months. In this thesis whenever there is a reference to “the current situation” or “after illness” this is referring to the third phase as defined in this chapter.
There will be respondents taking ART for 12 months while others may have been taking ART for 36 or even 72 months. Having people in this research who have been taking ART for differing periods of time it will also be possible to pay attention to the difference in duration and the effects this may have.

### 2.5.2 Well-Being

The Oxford Dictionary defines well-being as “a state of being healthy, happy, etc”. This is a rather static definition and appears to only consider one outcome, namely you are a ‘well’ being if you are in a state of being healthy and happy.

We should be moving away from this narrow conception of well-being towards a broader understand of well-being in which “well-being cannot be thought of only as an outcome, but as a state of being that arises from the dynamic interplay of outcomes and processes” (McGregor, 2006:3). Furthermore, following McGregor (2006:3) the conception of well-being “must combine the ‘objective’ circumstances of a person and their ‘subjective’ perception of their condition”.

This leads to the following definition of well-being, as defined by McGregor (2006:4): “In basic terms we conceive of well-being as arising from the combination of:

1. What a person has
2. What they can do with what they have, and
3. How they think about what they have and can do”

This now allows us to further operationalise the three models introduced earlier together with the above mentioned concepts; this can be brought together as follows:

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**Operationalisation of key-concepts and theoretical framework**

![Figure 2.7: operationalisation of the key concepts and theoretical framework](image)

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2.5.3 Insight & Impact

In order to provide an insight into the impact of ART on the well-being of HIV positive individuals and their households in Lusaka, Zambia a number of questions will need to be answered. First of all, evidence needs to be provided to show that PLHIV and their households do indeed differ from non-PLHIV and their households. Differences between PLHIV and non-PLHIV can demonstrate the impact that HIV may have had. The definition of well-being that was provided earlier is divided into three parts. Providing information on the personal characteristics and socio-economic status of people can provide an insight into the first part of the well-being definition. Providing information on how this group changes over time (Chronosystem) will allow for a better insight into the second part of the well-being definition. Additionally, looking at the different phases, as described above, and understanding how these influence the current well-being of people, can provide an insight into the impact of ART on people’s well-being. This allows us to look at the first and second part of the well-being definition. Looking at the third part of the well-being definition it is important that a broader understanding of how people value and influence their own trajectory of ART (from before illness to now) is gained. Finally it is important to look at the different conclusions and what they say about the interconnectedness of the theoretical framework. This can be operationalised as follows:

![Operationalisation - key questions](image)

**Figure 2.8: operationalisation – Key questions**

2.6 Research questions

In the previous section a number of key concepts were discussed and the operationalisation. In this section the key questions will be discussed and research questions will be formulated.
6.6.1 Part 1 – differences between PLHIV and non-PLHIV
This part will focus on the first key question: Does the study population differ from the general population? Differences in this context looks at how and what is different between the study population and the general population. In 2010 the author conducted research on the socio-economic impact of ART on PLHIV. In order to do this both a research and a control group were used in the study. This study provides a starting point in how the study group and the general population (control group36) differed in socio-economic terms. It also provided a number of results and conclusions. In Chapter 4 an overview of this research will be given. The following research questions were formulated:

- What are the personal characteristics and socio-economic situation of individuals and households that are not directly impacted by HIV?
- How do the personal characteristics and socio-economic situation of households of individuals receiving ART compare to those households that are not directly impacted by HIV?

2.6.2 Part 2 – Well-being
In part one a control and a research group exist, this allows for a comparison of the populations. However, in the rest of the research no control group was used and only PLHIV and their households are looked at. Part two will focus on key questions two to five. In Chapter 5 the second key question will be discussed: What are the personal and socio-economic characteristics of the study population. The study population refers to PLHIV and their households. The following research questions were formulated:

- What are the personal characteristics and socio-economic situation of individuals, and their households, receiving ART?

In Chapter 6 key question number three will be discussed: How does the study population change over time? In order to provide an answer to this personal characteristics and the socio-economic situation of PLHIV and their households was compared over time. The same PLHIV were interviewed in 2010 and 2012 and the responses were compared. The following research questions were formulated:

- How do the personal characteristics and socio-economic situation of individuals receiving ART, and their households, change over time?
- How does ART impact HIV positive individuals, and their households, socio-economically?

Households and individuals have gone through a period of transition; as such the factor of time will also be included. How do things change with time? Part of this has been looked at above, however, it does not compare the phases that individuals have gone through. In order to answer key questions four and five a better understanding of the trajectories people have gone through needs to be provided. How do past choices change the current outcome? When and why a person starts with ART will also influence their current situation. Do households who underwent a situation in which the PLHIV was bedridden differ today from households where the PLHIV on ART started with ART before they started suffering from frequent periods of illness?

36 The use of a control group allows for comparisons between the research group (PLHIV on ART and their households) and the general population in the same area. Seeing that HIV is endemic in Zambia there is a high risk that the control group also includes households that have been affected by HIV. Ideally the control group should not contain any individuals who are suffering from illness due to HIV or who are on ART, or households which have recently had a death as a result of HIV. In Chapter 4 the measures taken to minimise the chances of the control group containing individuals or households that are directly impacted by HIV are described.
In Chapter 7 the fourth key question will be answered: What factors (before illness and at start ART) influence the personal and socio-economic (current) outcomes of the study population? The following research questions were formulated:

- What were the personal characteristics and socio-economic status of individuals receiving ART before and at the start of ART?
- How do the personal characteristics and socio-economic status of individuals, and their household, before and at the start of ART determine the current well-being of individuals, and their households, receiving ART?
- How does ART affect the well-being of HIV positive individuals, and their households, who are receiving ART?

In the first section of Chapter 8 the fifth key question will be discussed: How do people value and influence the trajectory of ART, from before illness to now? In this section a closer look will be taken at the individual stories of PLHIV on ART. The following research question was formulated:

- How do HIV positive individuals, and their households, receiving ART understand and experience their current lives, and how does this compare to their life before HIV and when they first started with ART?

2.6.3 Part 3 – implications for theory

This part focusses on the last key question: What do the different conclusions say about the interconnectedness of the theoretical framework? This will be discussed in the second part of Chapter 8. By focusing on the interconnectedness of the model a more full understanding of the well-being of PLHIV on ART can be gained. The following research question was formulated:

- How do the different conclusions relate to each other and what does this say about the well-being of PLHIV on ART, and their households?

In the following chapter the research methods that were selected to collect the data will be discussed. In addition, the reasoning behind these choices will be made and the ethics involved in this study will be discussed.
Chapter 3 – Research Methodology

3.1 Introduction

In this chapter the research methodology of the research will be discussed. This research used both quantitative and qualitative methods, this will be discussed in section 3.2. In section 3.3 the extensive survey that was used in this research will be discussed. Close attention will be paid to the contents of the extensive survey, the sample populations, the sampling process, the training of interviewers, and the data analysis. In section 3.4 interviews will be discussed. Finally in section 3.5 the ethical considerations underlying this research will be discussed.

3.2 Qualitative and quantitative methods

Both qualitative and quantitative methods were used in this study. Cresswell (2003) explains that a mixed method approach is one in which the researcher collects, analyses, and integrates both quantitative and qualitative data in a single study. Within this two types of mixed approaches exist: mixed model and mixed method. A mixed model approach asks that quantitative and qualitative approaches are mixed within or across the stages of the research. A mixed methods approach instead asks for a qualitative phase and a quantitative phase. An example of a mixed model approach is using a questionnaire during data collection that includes both open-ended (qualitative) questions and closed-ended (quantitative) questions. In this study a mixed model approach is used; an extensive survey that includes both open and closed ended questions.

The main research tool that was used was an extensive survey. This survey includes both open and closed questions. There are a number of short open ended questions (for example: what are the main problems you are facing?), in addition, there are six questions which were structured as semi structured in depth interview questions. As such this survey provides both quantitative and qualitative data. A number of in-depth interviews were also conducted, amongst a number of people that also took part in the survey.

The research was conducted in Lusaka, the capital of Zambia. Lusaka has the highest HIV prevalence rate of the country. Additionally Lusaka is one of the few areas where ART has been available as early as 2004. In 2010 the author also conducted research in Lusaka thus by returning to Lusaka it was possible to re-interview people. Two urban areas were selected in Lusaka, to conduct the research in, namely Kalingalinga and Roma N’gome. These two areas, while both relatively poor areas, differ from each other socio-economically. In addition, Roma N’gome is on the very outskirts of Lusaka, while Kalingalinga has a far more central location. The differences between the areas will be discussed more in depth later in this section 3.2.2.

Key people from other areas in Lusaka were also spoken to and certain preliminary results were also discussed with them. Key people include coordinators from various projects under the CHBC, employees of the CHBC coordination office, care-givers, and counsellors from various clinics.

3.3 Extensive survey

3.3.1 Introduction

In this section a closer look will be taken at the survey that was designed for this research (a copy of this survey can be found in Appendix 1: Survey (English)). The survey includes a large number of topics and issues; these will be discussed in this chapter in relation to the operationalisation as presented in Chapter 2.
The survey consists of a number of sections and discusses a number of time periods as were defined in Chapter 2. The first section includes the current situation, the second part focuses on the period in which the respondent started ART, and finally a section about the situation before illness. Questions regarding the observed differences between the time periods were also included.

The extensive survey included questions both about the individual on ART as well as their household. In order to gain an insight into the impact and diversity of possible impacts of ART on individual and household level the first question asks people to tell us about their life and the story of their illness. This question was formulated as an open interview question and interviewers were trained in how to conduct open interviews (both how people were trained and why it was decided to use interviewers will be discussed in section 3.3.4).

The survey consists of a total of six of these open interview questions. These questions are devised to gain an understanding into the different stages that people have gone through:

- Could you please tell us your life story and the story about your illness?
- Could you please describe to us what your life was like before you became ill?
- Could you please describe to us what your life was like when you first started with ART?
- Could you please explain how and what has changed in your life comparing the period before you were ill up to the point that you started with ART?
- Could you please explain how and what has changed in your life between when you first started ART and how it is now?
- Could you please explain how and what has changed in your life between comparing the period before you were ill and how it is now?

These questions allowed us to get an insight into the condition/situation of people over the three periods. It allows for a better understanding of how lives may have been affected and to what extent. For example, asking someone if they were bedridden at the start of ART may be seen as problematic and creates a grey area: it asks us to define bedridden and then becomes a term that places people into two groups while in reality various degrees exist. The subjective experience rather than only the clinical or socio-economic situation may be captured better through this approach. This approach allows people to tell their story and focus on those factors, feelings, events, etc that they feel are important.

Household profiling for a number of characteristics was also conducted. Characteristics recorded here include: marital status, relations between household members, sex, age, education level (for both adults and children), occupation, income contribution to household (adults only), current school attendance, who pays the school fees, work, and whether or not a child is living with his/her biological parents and why – orphan status (children only).

Using the resource pentagon and knowledge on typical coping strategies a number of questions were devised to get an insight into the available resources. Questions include house ownership, access to electricity, food sources, income sources, household assets, tool ownership, access to tools, food production, assistance, etc.

Additionally a number of questions were asked to provide an insight into the nutritional situation in households, these include questions about meals (breakfast, lunch, dinner) and food security in terms of occurrence and frequency of food shortages as well as frequency of meals (for example two or three times per day).

As we are looking at PLHIV it is important to look at the health situation. Questions covering the mental and physical health were included in the survey. This can be brought back to the ecological model of health that was introduced in the previous chapter.
The survey was in part based on the survey from 2010. Questions that proved to be problematic in 2010 were adapted, changed, or even removed. A number of questions were added. The survey was discussed with the involved projects, the coordination office of the CHBC, and a number of experts. The survey was translated to Nyanja and the translated version was checked and compared to the English survey by a number of people. Additionally the translated survey was also discussed at length during the training of both research teams. Before the final surveys were printed a number of mock interviews were conducted in both Nyanja and English (field testing).

After careful deliberation it was decided to print the surveys in English and provide the interviewers with a Nyanja copy. The Nyanja spoken in Lusaka is not “pure” Nyanja, often different other local languages are mixed and even English words are included. The interviewers themselves experienced difficulties with the pure Nyanja that the survey was translated into and also explained that sometimes more than one word existed to explain something depending on the Nyanja spoken by the respondent.

3.3.2 Survey Population
The survey was conducted amongst PLHIV who had been receiving ART for a minimum of 12 months. Questions in the survey ask information about the individual but also about the household. During sampling it was ensured that not more than one person per household was interviewed. As such, households may include more than one person on ART however the survey would only be conducted with one of these household members.

The survey was conducted in two Urban areas of Lusaka, namely Kalingalinga and Roma N’gombe. In the map below the size and location of the two areas is depicted. Following this a brief description of the areas will be given.

![Study Areas in Lusaka](source: Google Maps modified by the author.)

*Figure 3.1: Map of Lusaka depicting the study areas*

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37 These include: Government social welfare officer; counsellors active at VCT clinics; medical doctors; nurses; and representatives of a number of churches, church based organisations, NGO and community based organisations.

38 The original translation was done by a Nyanja teacher and author of numerous teaching books for Nyanja.

39 These include: staff members at the coordination office; representative of the development office at the Archdiocese of Lusaka; Nyanja teacher and translator; and a counsellor of a VCT centre.

40 A copy of the English survey is included in Appendix 1: Survey (English). For a copy of the Nyanja version of the survey please contact the author.
• Kalingalinga compound\footnote{In Zambia a township is normally called a (shanty) compound. The word compound will be used for the remainder of this thesis.} is a settlement in the east of the city. It is one of the city’s older compounds and has a relatively long history. In 2007 Kalingalinga had an estimated population of between 35,000 and 45,000 people (LCC, 2008). While Kalingalinga used to be one of the poorest compounds in Lusaka this is no longer the case. Kalingalinga is home to many small businesses, such as brick making, stone crushing, furniture making, etc. The area appears to be thriving and there is activity everywhere; alongside the main road in Kalingalinga there are small stalls. Its geographic location within Lusaka has a number of advantages: it is easily accessible and borders to a number of well-situated residential areas. This will make it easier for businesses to flourish and alternatively for people to go and look for jobs outside the area.

• Roma N’gombe is a combination of different areas in Lusaka. It encompasses Roma, N’gombe, and part of Kalundu. Roma and N’gombe can both be classified as compounds, while Kalundu is largely a Residential area. N’gombe is a relatively new settlement and its legal status is still precarious. Its exact boundaries are hard to define, although most people use the river that runs along each side as a geographic marker. In 2000 the area of Roma N’gombe was estimated to have a population of 41,275 according to the government census. This figure however is likely to have changed over the years, especially since N’gombe has been expanding rapidly. The Residents Development Committee (RDC), in 2010, estimated that the population of this area was probably closer to 120,000 inhabitants. The area that Roma N’gombe covers hosts both relatively good as well as relatively bad compound areas. Its geographic location within Lusaka is not ideal: it is not easily accessible and (apart from Kalundu) is relatively far away from relatively well-situated residential areas. Residential areas are a source of employment and this in combination from the area being far away from business districts means that there are not many job opportunities in the area. In addition, there are not many business opportunities as consumers are not drawn to the area.

These two areas were chosen for a number of reasons. For both areas it can be said that the HBC projects are amongst the more successful projects of the Community Home Based Care (CHBC) Programme of Lusaka (see section 1.6 for details about the CHBC programme). The areas differ from each other in a number of ways: population, economic situation, geographic location, etc.

Previous research by the author was conducted in Roma N’gombe and was revisited in this research. This Home Based Care (HBC) project (see section 1.6 for details about HBC projects) was chosen previously for a number of reasons, including: it is amongst the oldest, it was one of the first projects that started distributing ART (as early as 2004), it had a relatively good database, and finally the catchment area of the project covers both relatively good as well as relatively bad compound areas.

The second site that was chosen, Kalingalinga, has better economic potential and can as such serve as a comparative site. Living in an economically better location, however, does not necessarily mean that socio-economic outcomes will be better. As such both differences and similarities can be, and were, compared.

### 3.3.3 Sampling

In this section the different sampling techniques for Roma N’gombe and Kalingalinga will be given. Sampling for Roma N’gombe stems from the sampling of the research that was conducted, by the author, in 2010. Figure 2.1 provides an overview of the sampling in 2010 and 2012 regarding the sampling location and sampling groups. It provides an overview of who the respondents were and what level was measured.

From figure 3.2 it can be seen that the sampling for Roma N’gombe was done in 2010 and the same people were re-interviewed in 2012. Sampling for Kalingalinga took place in 2012.
Sampling Roma N’gombe and Kalingalinga

Roma N’gombe

Sampling in Roma N’gombe was already done in 2010 and in the follow up research in 2012 people who participated in the 2010 research were revisited and asked to participate again. In 2010 the database at Roma N’gombe HBC included 445 people. From these 303 people were on ART at the time and 117 had been on ART for a minimum of 24 months. In total there were 102 people who fit the required criteria and were selected to participate in the research. From these 102 people 81 were found, able, and willing to participate. For the remaining necessary respondents a number of other methods were deployed. A number of people who had been part of the programme in previous years heard about the research and came to the centre to ask if they could participate. If they fitted the requirements they were included. For the remaining participants a list was drawn up from the database of the previous year. The last 30 people who had been removed from the register in the previous year that fit the requirements were asked to participate. In total 104 of the surveys that were conducted in 2010 were considered eligible and were included in the research results in 2010.

In 2012 the 104 participants that were included in the research results of 2010 were looked for and where possible asked to participate again. A total of 61 people were re-interviewed. The other 43 people were not re-interviewed for a number of reasons, of which the main two reasons were that people had moved (35%) or people were untraceable (32%).

Kalingalinga

Sampling 2012

In total 104 of the surveys that were conducted in 2010 were considered eligible and were included in the research results in 2010.
In figure 3.3 the reasons why 43 people that were not re-interviewed are displayed.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Died</td>
<td>12%</td>
</tr>
<tr>
<td>Moved</td>
<td>35%</td>
</tr>
<tr>
<td>Not found home</td>
<td>5%</td>
</tr>
<tr>
<td>Refused</td>
<td>7%</td>
</tr>
<tr>
<td>Sick</td>
<td>2%</td>
</tr>
<tr>
<td>Unable to come</td>
<td>7%</td>
</tr>
<tr>
<td>Untraceable</td>
<td>32%</td>
</tr>
</tbody>
</table>

Figure 3.3: Reasons why respondents from 2010 were not re-interviewed in 2012

Out of the 61 interviews, after careful revision, a total of 57 of these have been included in the results\(^{42}\). The data from 2010 and 2012 has been put into one database and for a number of factors can be, and were, compared.

**Kalingalinga**

In Kalingalinga a similar sampling strategy, as was used in Roma N’gombe in 2010, was followed. In 2012 the database at Kalingalinga HBC included 328 people. After carefully discussing the criteria (only people who were 18 years and above, had been on ART for a minimum of 12 months, and no more than one person per household was able to be selected) with the project co-ordinator the list was updated and there were 264 people remaining that were eligible to participate in the research. From these 100\(^{43}\) people were interviewed. The final list of people who were looked for and were asked to participate in the research contains 117 people. From these 117 people 100 were interviewed, 3 refused, and 14 were never found at home or had moved. In total 94 of the surveys that were conducted in Kalingalinga were, after careful revision, considered eligible and were included in the research results\(^{44}\).

### 3.3.4 Interviewers

In both Roma N’gombe and Kalingalinga people were trained to conduct the surveys. There are a number of reasons why the choice was made to train interviewers rather than conducting the interviews myself. Logistically it would have been impossible to conduct all the interviews myself. This was compounded by the fact that I do not speak fluent Nyanja or Bemba. Seeing that the majority of the people that were interviewed spoke little to no English this would have meant that I would have needed a translator with me throughout the process.

---

\(^{42}\) Reasons for exclusion include incomplete surveys as well as not meeting the criteria.

\(^{43}\) After the list of participants who were eligible was drawn up the names were put in random order. The first person on the list was then selected, following this two names would be skipped before the next person was selected, then again two names would be skipped, and so forth (The 1\(^{st}\), 4\(^{th}\), 7\(^{th}\) 10\(^{th}\), 13\(^{th}\), etc. person was selected. Upon reaching the end of the list counting continued to the start of the list.

\(^{44}\) Reasons for exclusion include incomplete surveys as well as not meeting the criteria.
The interviewers that were trained were in Roma N’gombe all from the HBC, and in Kalingalinga partly from the HBC and partly from outside the HBC. Training people from the project to conduct the interviews has advantages and disadvantages. The advantage is that there is an existing relationship of trust between the interviewer and the respondent. This may allow people to be more open and honest. This may particularly be the case where the respondent has already told and shared many details about themselves with the HBC staff. However, there are also a number of risks related to asking people from the project itself to conduct the interviews. The client-provider relationship, for example, lead to certain questions being answered in a specific way. It is after all difficult to say something negative about an organisation when discussing this with an organisation. Similarly knowledge that someone may have learnt from that organisation may more easily be repeated than that someone provides new insights. People may also feel that it is in their benefit to make their situations ‘worse’ in the hope that they may receive some additional support.

**Roma N’gombe**

In 2010 a total of four people (three women and one man) from the Roma N’gombe HBC project were trained to complete the surveys. These four people are still part of the Roma N’gombe HBC project and were retrained and asked to conduct the surveys in 2012.

Because the survey is rather extensive and also includes a number of semi-structured interview questions which would need careful recording it was decided to pair the interviewers. In the research team in Roma N’gombe there are two interviewers who are very competent in English and Nyanja while the other two interviewers struggle with their written English. Each pair was made up of one very competent English speaker and one less competent English speaker.

**Kalingalinga**

In Kalingalinga a total of five people were trained. Two were from the project and three were from outside the project\(^45\). In Kalingalinga each project member was paired to one external interviewer who was not part of the project – as a measure to ensure data quality. The three interviewers that were not part of the project were interviewed beforehand and needed to have completed at least secondary school. The fifth person who was trained had previous experience with surveys and research and would serve as an extra quality control. Doing research in two locations simultaneously meant that I would not be able to be in both places at the same time. The fifth person functioned as my research assistant for this site, where research experience was limited to non-existing amongst the rest of the research team.

The interviewers were trained in two groups; one in Roma N’gombe and one in Kalingalinga. The survey was thoroughly discussed with both groups and each question was practised. After having discussed the questions in a particular section of the survey the interviewers were asked to practice these sections. When all questions had been discussed and practised the survey was then performed as a whole. First the interviewers would interview each other and the group would be asked to comment and provide feedback at the end. At the end a number of PLHIV from the project were asked to come for interviews in order for the interviewers to practice.

The interviewers were also trained in open interviews. They were first provided with an explanation and were then asked to interview each other. These mock interviews were then evaluated. Feedback was provided by me and the group was also asked to provide positive criticism and feedback. Finally a number of difficult scenarios were also enacted as a means to prepare the interviewers for varying situations.

\(^45\) In Roma N’gombe a similar strategy was considered. However, after careful discussions with the project co-ordinator at Roma N’gombe and the overall programme director it was decided to keep the same research team as was used in 2010. No more than 4 interviewers were needed to complete the surveys. Introducing more would not only be costly but may also have led to the data quality being reduced. Reducing the original research team, in order to add new external members, may have caused conflicts within the HBC.
3.3.5 Data Analysis
Surveys were recorded directly onto the survey form, and for the open interview questions hard cover A4 note books were provided. Once completed, these were immediately checked and where it was necessary queries were discussed with the interviewers. In a number of cases this meant that the interviewers had to go back to the respondents. Once this process was completed the surveys were again checked and then entered into the computer. For the quantitative parts (which were coded) the data was entered into STATA (StataCorp LP, STATA Data Analysis and Statistical Software, version: 10.1), and the qualitative parts (open interviews and open questions) were typed up and later entered into MaxQDA (MAXQDA is produced and distributed by VERBI GmbH, Version:11).

3.4 Interviews
Various interviews were conducted using various sampling techniques.

During a period of eight months numerous projects of the CHBC were visited. These included projects in urban, rural, and peri-urban areas. During these visits project coordinators were interviewed. These interviews were not recorded as they often started out, in the field, as a conversation. Instead, notes were taken and the conversations were later written up. Occasionally, also clients who happened to be present during the visit were interviewed.

The CHBC coordination office staff, particularly the field officers, provided me with key information throughout the eight months that I was in Zambia and part of their office. Their advice and information was written up for later referencing. Some of the information came from specific questions I had, but often they brought me information that they felt could be of use.

Interviews with some of the people from research teams were also conducted. Their experiences as well as their extensive knowledge of the situation at large and that of their clients proved invaluable. Interviews with experts who were not part of the CHBC also took place. Sometimes these interviews were by chance and other times a meeting was set up. These interviews often led to more interviews (snow ball effect).

Finally, a number of interviews were conducted with respondents who were part of the survey. While all respondents had already provided their story and feelings in the open questions in the survey a number of respondents were asked if they were willing to participate in an in depth interview.

3.4 Ethical considerations and dilemmas

3.4.1 Introduction
When conducting research a number of ethical principles need to be considered. Conducting interviews with PLHIV asks for a careful approach and a lot of reflexivity of the researcher. The four main ethical areas that are often mentioned in social research (Diener & Crandall, 1978) are:

- Whether there is harm to participants
- Whether there is a lack of informed consent
- Whether there is an invasion of privacy
- Whether deception is involved

The research population is a vulnerable group that is prone to stigma, whether it be from outside sources or in the form of self-stigma, and as such asks for a careful approach. The research population is HIV positive and on medical treatment and their participation in this research should be protected and voluntary.
3.4.2 Research population

PLHIV are often at risk of stigmatisation and if this occurs because of the participation in this research then the research can be seen as harmful to the participants. The PLHIV that were part of the research were all part of an HBC project. They have contact with the project often through care givers visiting their homes. As such it was decided that the first contact with the participants would be made through one of these visits from their regular care giver. The care givers were asked to explain the purpose of the research and ask the respondents whether or not they would be willing to participate. If the participant agreed they would be asked to visit the HBC centre where the interview would be conducted. The interviews were deliberately done at the centre and not at the respondents' homes. This was done out of protection of the respondents; while neighbours may not react to seeing someone visit a home on a regular basis (like a care giver), people instead may be suspicious to strangers. Additionally houses are often not far apart and this could lead to people overhearing the interview. Suspicious behaviour or the overhearing of private information may lead to questions, gossip, or even stigmatisation of the respondent. To avoid this people who were willing to take part in the research were asked to visit the centre. Through the care givers an appointment would be made for them to come to the centre.

In the first contact between the respondent and the care giver information regarding the research was already provided. In addition people were asked if they were willing to participate. However, in order to ensure an as best as possible informed consent, participants were again informed at the start of the interview. Interviewers were instructed to inform the participants, again, of the purpose of the research and the reason why they had been asked to take part in this research. This has both to do with informed consent and with ensuring that participants were not deceived. Interviewers were told to ensure that participants were aware that their participation was voluntary and that if at any point during the interview they felt uncomfortable or preferred not to answer certain questions they should feel free to say so and that the interview would be stopped or certain questions would be skipped accordingly. None of the participants stopped the interview or refused to answer any of the questions. In addition people were informed that all the data collected would be confidential and anonymous. In this thesis no names of participants or information regarding the participants that could link specific people to this research is mentioned.

Once the interviews were completed participants were asked if they had any questions, comments or suggestions. People were also told that if they had any questions later on they should feel free to return to the centre. The project coordinator would try and answer these questions as best as possible, and if necessary an appointment could be made with me. It should be mentioned that this never happened.

Regarding the privacy of the respondent a number of things need to be taken into consideration. Privacy has partly been discussed in terms of their anonymity and the location of the interview. In addition there are a number of other ethical concerns. Certain questions may cause respondents to feel uncomfortable and at worst even cause them emotional distress. It may, for example, be difficult for people to discuss their illness or past situations regarding their illness. This may be seen as a private matter and as such be seen as an invasion of privacy. Discussing certain past events may ask of people that they remember periods that they wished never happened and would like to forget, this could be considered as harmful to participants. In order to avoid this, a combination of closed and open questions was devised. The open questions asked the participant to recall certain periods and processes but allowed them to, largely, decide on the content themselves. While the closed questions asked fewer emotional issues. As mentioned previously, respondents were informed that if they felt uncomfortable or preferred not to answer certain questions these could be skipped or the interview could be stopped.

Another form of deception that is often difficult in research is whether or not participants are paid or not. In this research paying participants was not an option. The policy within the CHBC does not allow for payment. It was however decided, and is a common practice within the HBC and CHBC, that participants would be provided with
a drink and a bun during the interview. Participants were made aware immediately that participation was voluntary and that they would not receive any form of payment.

The research population is part of the HBC projects, this has many advantages but also a number of disadvantages which also give rise to a number of ethical considerations. Because people are part of a project and this project has supported them they may feel pressurised to participate in the research as they may feel they owe the project something. Through informing participants at least twice that participation is voluntary we hope that people did not feel pressured. This is however something that cannot be guaranteed.

Not all PLHIV in Zambia are part of an HBC and as such part of the population is missing. The sample population as such is not perfect. Additionally information on people who have passed away is missing.

3.4.3 Key interviews
Key interviews with participants from the survey were conducted only after the survey had taken place. As such people were already aware of the research and that participation was voluntary. People who were invited for an interview were again asked if they were willing and informed about the purpose of the interview. The interviews were held at the centre and where necessary someone from the research team would act as translator.

Participants were again informed about the research, their participation, and the purpose of the research. In addition, participants were again told that their answers would be kept confidential and anonymous. Next the topics that would be covered were discussed with the participants and they were informed that if they felt uncomfortable or wished to skip any they were free to say this at any point.

With regards to other key interviews everyone was aware that I was doing research and what the purpose and topic of this research was.
Chapter 4 – Research 2010

4.1 Introduction

In this chapter an overview of the research that was conducted in 2010 will be given, including a short overview of the research design, main results, and conclusions. The research conducted in 2012 builds on the 2010 research. This chapter serves as an introduction to the 2010 research. In addition this chapter serves as a means to answer the first part of the research questions. The questions that will be answered are:

- What are the personal characteristics and socio-economic situation of individuals and households that are not directly impacted by HIV?

How do the personal characteristics and socio-economic situation of households of individuals receiving cART compare to those households that are not directly impacted by HIV?

4.2 Research Design

The research conducted in 2010 had the following research aim:

To provide an insight into some of the socio-economic effects of cART on HIV infected individuals and their households in Lusaka, Zambia.

The research included a number of important terms that were also used in the research that was conducted in 2012, namely: insight and the three phases (before illness, during illness - start cART, after illness – current situation).

The main research questions were formulated as follows:

- What are the personal characteristics of HIV positive individuals receiving cART and their households and how does this compare to the personal characteristics of individuals and their households in the control group.
- How do the personal characteristics of the HIV positive individuals receiving cART and their households compare to their and their households’ personal characteristics during the period that they were ill?
- How do the present personal characteristics of the HIV positive individuals receiving cART and their households compare to their and their households’ personal characteristics to before they were ill?
- How do the personal characteristics of the HIV positive individuals receiving cART and their households compare to one another dependant on the duration of cART?

The research design was experimental, whereby both a research group (PLHIV on cART for a minimum of 24 months) and a control group were included. The main research tool was a survey which was split into the three previously mentioned phases. The research group answered questions on all three phases, and the control group was asked questions only about the current situation. The survey that was developed included questions.

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46 It should be noted that in this chapter the term cART is used while in the rest of the thesis the term ART is used. The term cART stands for comprehensive antiretroviral therapy. In 2010 this was the correct term to use, however this is no longer the case.
regarding: household build up, characteristics of household members, economic activity, economic situation, problems faced by households and people on cART, and received assistance.

The research was conducted, as previously mentioned, in Roma N'gombe. More information about the research area, population, and sampling can be found in Chapter 3 in section 3.3.2.

The control group was determined through the nearest neighbour technique, whereby a household member of the house to the left of the respondents' house was asked to participate. Respondents were informed that their neighbours would be interviewed. The control group was informed that this was for research purposes; however, the terms HIV were not included as a means to protect the respondents of the research group. The use of a control group allows for a comparison between the research group and the general population in the same area. However, seeing that HIV is endemic in Zambia one should be aware that there is a high risk that the control group would also include households in which a household member may be ill, or even on cART. While it could be argued that this is simply a reality for the general population it does pose problems if we are researching the impact of cART. Ideally the control group should not contain people who are suffering from illness due to HIV or who are on cART, or households who have recently had a death as a result of HIV. This posed a challenge seeing that we could not ask people about their and their household members HIV status or even about HIV related recent deaths. This is both ethically problematic, but also poses risks to the respondents who were included in the research group. The interviewers were all part of the HBC project (for more information please see Chapter 3 section 3.3.2) and were asked to, together with the care givers, create a sort of profile of the neighbouring houses and discuss which households contained people who were suffering from illness due to HIV or who are were on ART, or households who recently had a death as a result of HIV. The interviewers were instructed to skip these households and proceed to the next house to the left.

From the research group a number of participants were selected to be invited to participate in interviews. These semi-structured interviews were conducted with a total of nine participants. In addition key interviews were held with a number of people, including: project members, coordination office staff, and other key people. The interviews were not recorded but written up and later typed out.

4.3 Results

4.3.1 Data collection

In total 210 surveys were completed, 105 in the research group and 105 in the control group. Information was gathered on all household members of the people that were interviewed. The total number of people, including both the interviewed people and the other members of their households, was 1036 of which 536 were adults and 245 (45.7%) were male and 291 (54.3%) were female giving a male to female ratio of 1:1.2. The male/female distribution amongst the children is more equally distributed, namely: 254 (50.8%) male and 246 (49.2%) female. The average age for adults was found to be 37.1 years and that of children as 8.8 years. The average household size of the research group is 4.8 compared to 5.1 in the control group. Each household has an average of 2.4 children in both the research group and the control group.
<table>
<thead>
<tr>
<th></th>
<th>Research group</th>
<th>Control group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Total number of people</td>
<td>502</td>
<td>100.0%</td>
</tr>
<tr>
<td>Number of children (&lt;18 years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>252</td>
<td>50.2%</td>
</tr>
<tr>
<td>Female</td>
<td>130</td>
<td>25.9%</td>
</tr>
<tr>
<td></td>
<td>122</td>
<td>24.3%</td>
</tr>
<tr>
<td>Number of adults (18 years +)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>250</td>
<td>48.8%</td>
</tr>
<tr>
<td>Female</td>
<td>105</td>
<td>20.9%</td>
</tr>
<tr>
<td></td>
<td>145</td>
<td>28.9%</td>
</tr>
</tbody>
</table>

Table 4.1: Figures about the research group and control group

Table 4.1 shows that the number of male adults is lower in the research group than in the control group.

The main findings were described as follows:

- Looking at age differences between the groups it at first hand appears that there are differences: where the median age in the research group is 36 and 32 in the control group. When looking at the 25th and 75th percentile it appears however that there is not much difference.

<table>
<thead>
<tr>
<th></th>
<th>Research Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>25th percentile (Q1)</td>
<td>24.5 years</td>
<td>23.5 years</td>
</tr>
<tr>
<td>Median</td>
<td>36 years</td>
<td>32 years</td>
</tr>
<tr>
<td>75th percentile (Q3)</td>
<td>45 years</td>
<td>46 years</td>
</tr>
</tbody>
</table>

Table 4.2: Age of adults in research and control group

- In 2008 women made up 50.1% of the Zambian population (World Bank, 2010), in this research the male-female ratio between the ages of 25-49 in the research group differs from this. The male to female ratio in the research group was 1:1.9 and 1:1.1 in the control group. Women in this age group also appear to be more likely to be widowed when in the research group than when in the control group (p<0.001).

- In terms of marital status it was found that for children (age <18 year of age) in both groups all children were single. When looking at the adults a difference can be seen: in the research group a larger percentage of widowed and divorced people was found than in the control group. Additionally more single headed households were found in the research group than in the control group.

<table>
<thead>
<tr>
<th></th>
<th>Research Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>31%</td>
<td>35%</td>
</tr>
<tr>
<td>Married</td>
<td>42%</td>
<td>53%</td>
</tr>
<tr>
<td>Separated</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>Divorced</td>
<td>8%</td>
<td>4%</td>
</tr>
<tr>
<td>Widowed</td>
<td>18%</td>
<td>7%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 4.3: Marital status of adults in research and control group

- The majority of the children were living with a biological parent. 65.9% of the children in the research group were living with at least one biological parent compared to 72.2% in the control group. 19.1% of the children in

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47 This calculation is based on a chi-square test.
the research group lived in a household which was headed by a grandparent, compared to 12.9% in the control group.
- 40% of the children in the research group has lost one or both parents, in the control group this is 25%. Children in the control group are more likely to be living with both their parents and are less likely to have lost a parent (p<0.001)\(^{48}\) than children in the research group.
- For both the control and the research group 80% of the children of seven years and above is said to be attending school.
- There is virtually no difference in education levels of the adults between the groups. For both groups 60% has completed at least primary school, and 10% has had no education at all.
- Most children above the age of seven are said to do some form of work, this is the case in both the control and the research group, the work referred to is work around the house. Below the age of seven they are said to be too young. A total of 17 children is said to be working for payment/profit. 12 of these are in the research group (2 in the age category 7-9, and 10 in the age category 10-17) and 5 in the control group (all are in the age category of 10-17).

4.3.2 Research findings

Becoming HIV positive then starting cART and then continuing with one`s life is a trajectory that all respondents in the research group have gone through. The story for each respondent is unique and the process is experienced differently by everyone. However, similarities do exist, both in story line and experience as well as in difficulties and outcomes.

Looking at the current situation it can be seen that people are indeed recovering their lives but things have changed. With regards to this most respondents report the following:

- They have physically recovered but their physical strength is not the same as it used to be
- While people are now able to return to work they are encountering difficulties in recovering their employment status
- Assets have been sold or traded and are thus now unattainable
- Some resources cannot be recovered: many women lost their husbands and these partners cannot be replaced
- Lives are not restored in a day. It takes time for people to build up their lives again.

Taking a close look at the data resulted in the following main research findings:

- **Physical strength:** most respondents reported that their physical health quickly recovered after starting cART. However, when asked to compare their lives to before they were ill many respondents mentioned that their physical strength is not as good as it used to be. 41% of the respondents report that their strength is not the same as it was before they got ill.

- **Employment:** most respondents (79%) were no longer performing any form of work at the start of cART. While 96% of the respondents reported that they were now working again the type of work, when compared to before they became ill, differs. The percentage of people working for payment/profit has decreased, from 69% before illness to 48% now. Those people who no longer work for payment/profit now mainly do chores around the house (40% now compared to 19% before). Respondents report that they do seek for some form of employment but find it difficult to find employment. The labour market in Zambia is tough and there are not enough jobs. Respondents may have lost their previous employment and are now unable to return to their old jobs. Alternatively people may have had a business but

\(^{48}\) This calculation is based on a chi-square test.
now do not have the means to start up this business again. Additionally some jobs may no longer be an option; many respondents reported that they could no longer “work hard jobs”.
Over time the situation improves. The longer people have been on cART the larger the percentage of people working for payment/profit is.

- **Income**: There is a difference between the main source of income between the research group and the control group. There are three main income sources, namely formal employment, piece work\(^{49}\), and own business. Formal employment is the most stable source of income while piece work is probably the least stable. 40% of the control group states that formal employment is the main source of income compared to 32% in the research group. Piece work is more common in the research group where this is 32% compared to 26% in the control group. Businesses comprise 25% of the research group’s main source of income compared to 21% in the control group.

Comparing people who have been on cART for 4-6 years to those on ART for 2-3 years it can be seen that the situation improves with time. In the 4-6 years group the percentage (39.7%) of people working in formal employment is almost the same as that in the control group, while in the 2-3 years group this is much lower (22.5%). This leads to a decrease in the number of people depending on piece work as their main source of income in the 4-6 years group.

<table>
<thead>
<tr>
<th>Income source</th>
<th>Research Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>Duration cART</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 to 3 years</td>
</tr>
<tr>
<td>Formal employment</td>
<td>32.4%</td>
<td>22.5%</td>
</tr>
<tr>
<td>Piecework</td>
<td>32.4%</td>
<td>40.0%</td>
</tr>
<tr>
<td>Own Business</td>
<td>24.8%</td>
<td>25.0%</td>
</tr>
<tr>
<td>Other</td>
<td>10.5%</td>
<td>12.5%</td>
</tr>
<tr>
<td>Total</td>
<td>100.1%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

*Table 4.4: Employment status research and control group*

While people do recover and with time things at first hand appear to be comparable to the control group this is not the whole story. Income levels for the households on average are lower in the research group, and while after 4-6 years things have improved, this is still not comparable to the control group. The average household monthly income in the control group, with just under half a million Kwacha (~€78), is higher than that of the research group, with just over three hundred thousand (~€49). Households where a household member has been on cART for 2-3 years has an average monthly income of K261,262 (~€42) while households where the household member has been on cART for 4-6 years has an average monthly income of K348,545 (~€56).

<table>
<thead>
<tr>
<th>Income source</th>
<th>Research Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>Duration cART</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 to 3 years</td>
</tr>
<tr>
<td>Mean income (total)</td>
<td>ZMK 302,347.00</td>
<td>ZMK 261,262.00</td>
</tr>
<tr>
<td></td>
<td>(n=98)</td>
<td>(n=37)</td>
</tr>
<tr>
<td>Mean income (formal employment)</td>
<td>ZMK 377,186.00</td>
<td>ZMK 296,250.00</td>
</tr>
<tr>
<td></td>
<td>(n=32)</td>
<td>(n=8)</td>
</tr>
</tbody>
</table>

*Table 4.5: Monthly household income research and control group*

While the income source for households where people have been on cART for 4-6 years appears to be very

---

\(^{49}\) Piecework is a term widely used in Zambia. Piece work is part time work which people search for on a day to day basis and for which he or she is payed a fixed amount per job.
similar to that of the control group, the average monthly income remains higher in the control group. Households where the main source of income is formal employment are generally better off than households relying on other sources of income. For the control group this is K710,829 (~€115) and for the households where people have been on cART for 4-6 years this is K408,739 (~€66). For both groups households where formal employment is the main source of income have an average monthly income that exceeds the average for the whole group by far. However, the control group’s average monthly income still exceeds the average monthly income of households where there is a person on cART.

People themselves were also asked to compare their income over the three periods. Respondents not surprisingly reported that their income is better now than when they started cART, and in addition almost 75% of the people also indicate that their household income was better before they became ill compared to now.

- **Assets**: All respondents were asked if the household owned a TV, Radio, Bed or a Phone. For all the previously mentioned assets the households in the control group respond yes more frequently than in the research group. While 60% of the households in the control group said to own at least one TV this is 44% in the research group. For the other assets around 7% more households in the control group owned at least one of the items compared to the research group.

The percentage of households that own a specific asset increases the longer people have been on cART.

<table>
<thead>
<tr>
<th>Asset</th>
<th>Research Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>Duration cART</td>
</tr>
<tr>
<td></td>
<td>2 to 3 years</td>
<td>4 to 6 years</td>
</tr>
<tr>
<td>TV</td>
<td>44.2%</td>
<td>39.5%</td>
</tr>
<tr>
<td>Radio</td>
<td>41.3%</td>
<td>36.8%</td>
</tr>
<tr>
<td>Bed</td>
<td>76.9%</td>
<td>68.4%</td>
</tr>
<tr>
<td>Phone</td>
<td>60.6%</td>
<td>57.9%</td>
</tr>
</tbody>
</table>

*Table 4.6: percentage of households that own a specific asset*

Further analysis shows that the total number of assets increases the longer people have been on cART.

<table>
<thead>
<tr>
<th>Asset</th>
<th>Research Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>Duration cART</td>
</tr>
<tr>
<td></td>
<td>2 to 3 years</td>
<td>4 to 6 years</td>
</tr>
<tr>
<td>TV</td>
<td>0.45</td>
<td>0.42</td>
</tr>
<tr>
<td>Radio</td>
<td>0.42</td>
<td>0.37</td>
</tr>
<tr>
<td>Bed</td>
<td>1.16</td>
<td>1.00</td>
</tr>
<tr>
<td>Phone</td>
<td>0.87</td>
<td>0.87</td>
</tr>
</tbody>
</table>

*Table 4.7: amount of assets owned per household*

### 4.4 Main conclusions 2010

The data shows that people who start cART begin a long recovery process. Their health improves as does the socio-economic situation of their households. The data indicates that after 2 to 3 years on cART substantial improvements are visible both in terms of the patient’s health as well as the economic well-being of the households. Clear differences do however still exist between these households and those in the control group. After 4 to 6 years on cART we see even more improvement and at a first glance it may appear that people have regained their previous health and socio-economic status. Further inspection however reveals that even after 4 to 6 years of cART households are still not at the levels found in control cases. For example, the data reveals that
after 4 to 6 years of cART households have managed to regain their sources of income. While this is true, the data also shows that while people may have found a new job, their salaries are much lower.

In conclusion cART does allow people to regain a large part of their health, quality of life, and livelihood. At first this process goes quite rapidly and to a large extent we can say that they are able to continue with their lives. However, after this initial rapid improvement it will take a much longer period to recover to where they were before they got ill. Additionally, the data collected does not indicate that people will actually ever recover fully. The more a person loses, the more that person will later have to recover and, the harder it will become to recover what is lost.

4.5 Conclusions – research questions part 1

The research in 2010 serves as a baseline and as a means to answer part one of the research questions. By comparing the research group to a control group differences and similarities can be seen and discussed.

In this chapter an overview of the research that was conducted in 2010 has been given. Characteristics of individuals and households that are (research group) and are not (control group) directly impacted by HIV have been looked at and compared. What was seen is that the control group in general had a better socio-economic situation than the research group. The longer people had been on cART the closer their socio-economic situation came to the control group. However, even after 4-6 years people had not managed to get to a comparable level as the control group.

“I was strong and life was good before I became sick but now, although I am better, I am not as strong and life is not as good as it used to be before I became sick”

35 year old woman
Chapter 5 – Situation of PLHIV in Lusaka in 2012

5.1 Introduction

In the previous chapter the research conducted in 2010 was discussed and the first research question was answered. In the following chapters the data collected in 2012 will be discussed. In this chapter an overview of the data collected regarding the current situation of the respondents will be provided. In Chapter 6 the panel data that was collected will be discussed. Chapter 7 will provide a more in depth analysis of the data will be provided, here the different time periods people went through will also be discussed. Chapter 8 will take a closer look at the qualitative data that was collected. Following this a closer look will be taken at how the different conclusions and chapters relate to each other. Following these data chapters the final chapter, Chapter 9, will discuss the conclusions and recommendations.

In 2010 a control group was used, in 2012 this was not the case. The research in 2010 aimed to provide an insight into the socio-economic situation of PLHIV on ART and how this compared to the general population. In 2012 the focus lies on well-being of PLHIV. Here a more focused look is taken at PLHIV on ART and their households. Two different areas were selected and compared. PLHIV on ART who were interviewed in 2010 were re-interviewed in 2012 and the data was compared over time. This research focuses on the various factors that may influence the well-being outcomes of PLHIV on ART, rather than (as was the case in 2010) only showing an existing difference between PLHIV on ART and the general population.

As described in Chapter 3, surveys were conducted amongst PLHIV on ART in Kalingalinga and Roma N’gombe. The level measured included both the respondent (PLHIV on ART) and their household. This chapter will provide an overview of the data that was collected; both the data collected in Roma N’gombe and in Kalingalinga will be introduced. The majority of the data presented in this chapter comes from the extensive survey, while the interview data is mainly used indirectly as a means to provide a better understanding of the collected data and the answers provided in the survey.

In this research a large number of personal characteristics, of all household members, were collected. Characteristics that were collected through household profiling include the following: age, sex, marital status, relationship to the head of the household, work, financial contribution to household, school attendance, type of work children participate in, and whether the parents of the children in the households were present or not. In addition a number of characteristics were collected on the household itself, these include: house ownership, access to and type of access to water, access to electricity, etc.

A number of health characteristics were also collected with regard to the respondents (PLHIV on ART). These questions discuss both the physical and mental health of the respondent. This data was not collected for all household members but only for the person (PLHIV on ART) that was interviewed.

The focus of this chapter will largely lie on the personal characteristics collected for all household members. This will provide an overview of the research population in both areas. Additionally some household characteristics will be discussed. Finally a number of health characteristics of the respondents will also be discussed. This will be followed by a summary of the general findings and finally a conclusion and discussion.

This chapter serves to answer part of the research questions from part 2 (well-being). The following questions will be addressed in this chapter:

- What are the personal characteristics and socio-economic situation of individuals, and their households, receiving ART?
5.2 General overview of data collected

5.2.1 Data collected on sample populations

In total 161 surveys were completed, after data entry, data cleaning, and careful consideration ten surveys were removed from the dataset\(^{50}\); the remaining 151 surveys were analysed. From these a total of 94 come from Kalingalinga and 57 from Roma N’gombe.

| Number of households in Roma N’gombe surveyed | 57 | 37.8% |
| Number of households in Kalingalinga surveyed | 94 | 62.2% |
| Total number of households surveyed | 151 | 100.0% |

*Table 5.1: Number of households surveyed*

| Total number of people in Roma N’gombe | 284 | 42.2% |
| Total number of people in Kalingalinga | 379 | 57.8% |
| Total number of people | 663 | 100.0% |

*Table 5.2: Number of people living in the households being surveyed (research population)*

| Number of children (<18 years) within total number of people | 259 | 39.1% |
| Total number of Adults (>=18 years) within total number of people | 404 | 60.9% |
| Total number of people included in survey | 663 | 100.0% |

*Table 5.3: Number of adults and children in research population*

<p>| Roma N’gombe | Kalingalinga |</p>
<table>
<thead>
<tr>
<th>Number</th>
<th>Percentage</th>
<th>Number</th>
<th>percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of people</td>
<td>284</td>
<td>100.0%</td>
<td>379</td>
</tr>
<tr>
<td>Adults (18 and above):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>71</td>
<td>25.0%</td>
<td>117</td>
</tr>
<tr>
<td>Female</td>
<td>88</td>
<td>31.0%</td>
<td>128</td>
</tr>
<tr>
<td>Children (below 18):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>63</td>
<td>22.2%</td>
<td>61</td>
</tr>
<tr>
<td>Female</td>
<td>62</td>
<td>21.8%</td>
<td>73</td>
</tr>
</tbody>
</table>

*Table 5.4: Number of male/female adult/children in research locations*

From the 304 adults, 188 (46.5%) was male and 216 (53.5%) was female giving a male to female ratio of 1:1.15. The male/female distribution of children is as follows: 124 (47.9%) males and 135 (52.1%) female. The average age for adults was found to be 36.5 years and that of children 9.5 years. The average household size was 4.4 for the whole group; and 5.0 in Roma N’gombe and 4.0 in Kalingalinga. The average number of children per household for the whole group is 1.7, for Roma N’gombe this is 2.2 and for Kalingalinga this is 1.4; this difference is statistically significant\(^{51}\).

---

\(^{50}\) Reasons for exclusion include incomplete surveys as well as not meeting the criteria.

\(^{51}\) Based on T-test with Welch estimation.
The population pyramid for the total number of people surveyed looks as follows:

![Population pyramid](image)

**Figure 5.1: Population pyramid**

The above population pyramid does not have the typical shape that one would expect in a developing country. However, this pattern is not completely unexpected if one takes into consideration the impacts of the HIV epidemic in Zambia. Patterns like the one above have been predicted, for other countries in the region, as a result of HIV (see also Oramasionwu et al, 2011, Stanecki, 2002). Oramasionwu et al. (2011:2972) explain that for countries with high sero-prevalence these countries will “progressively veer away from the traditional pyramid shape with a predominant loss of the younger and adult populations”. In the population pyramid above there are two visible gaps in the pyramid for both males and females. The first is in the age between 25 and 49, which is also the age group that runs the highest risk of getting infected with HIV and thus, in the past, dying. Traditionally population pyramids in developing countries depict that the base of the pyramid is the broadest point; the largest group comprising of children in the age group 0-4. In the pyramid above we can see that this model is not followed and the largest group is found amongst children in the 15-19. Seeing that there are fewer adults between 20 and 40 and assuming that the number of children born per woman remains the same then it is to be expected that there are also less children born. The fertility rates for Zambia have been slowly decreasing from 6.5 in 1990, 6.2 in 2000, and 5.7 in 2009 (WHO, 2011:159). This would imply that even less children will be born. Oramasionwu (2011:2973) explain that, in the case of South Africa, they see that the percentage of the adult population is decreasing while the elderly population is increasing. They suggest that this is a “result of decreasing fertility rates among women, low levels of life expectancy among children born with HIV/AIDS, and adult mortality (Oramsionwu, 2011:2973).
Age
The median age for adults is listed below:

<table>
<thead>
<tr>
<th></th>
<th>Roma N’gombe</th>
<th>Kalingalinga</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>25&lt;sup&gt;th&lt;/sup&gt; percentile (Q1)</td>
<td>22</td>
<td>22</td>
<td>22</td>
</tr>
<tr>
<td>Median</td>
<td>36</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>75&lt;sup&gt;th&lt;/sup&gt; percentile (Q3)</td>
<td>47</td>
<td>45</td>
<td>45.5</td>
</tr>
<tr>
<td>Mean</td>
<td>36.5</td>
<td>36.4</td>
<td>36.5</td>
</tr>
</tbody>
</table>

*Table 5.5: Age for adults*

<table>
<thead>
<tr>
<th></th>
<th>Roma N’gombe</th>
<th>Kalingalinga</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>25&lt;sup&gt;th&lt;/sup&gt; percentile (Q1)</td>
<td>6</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Median</td>
<td>10</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>75&lt;sup&gt;th&lt;/sup&gt; percentile (Q3)</td>
<td>14</td>
<td>14</td>
<td>14</td>
</tr>
<tr>
<td>Mean</td>
<td>9.9</td>
<td>9.1</td>
<td>9.5</td>
</tr>
</tbody>
</table>

*Table 5.6: Age for children*

The age distribution for adults and children is statistically not different in the two research areas.

Sex
In 2010 51% of the Zambian population was female (CSO, 2011:1), in this research 53.0% is female. Earlier it was noted that there are less people than expected in the age category 20-49, for this group the following was found:

<table>
<thead>
<tr>
<th></th>
<th>Roma N’gombe</th>
<th>Kalingalinga</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>31.4%</td>
<td>43.8%</td>
<td>39.3%</td>
</tr>
<tr>
<td>Female</td>
<td>68.6%</td>
<td>56.2%</td>
<td>60.7%</td>
</tr>
<tr>
<td>Male:Female Ratio</td>
<td>1:2.2</td>
<td>1:1.3</td>
<td>1:1.5</td>
</tr>
</tbody>
</table>

*Table 5.7: Sex of age group >=25 & <=49*

From the above we can see that there are more women than men in general and in particular in the age group 25 to 49 years in the research population. In Roma N’gombe this difference is even bigger where there are 2.2 women per every man, compared to 1.3 women per man in Kalingalinga. The number of women per men in the same group in 2010 in Roma N’gombe was 1:1.9; as such there are even fewer men per woman in 2012 than there were in 2010.
Marital status

All children (<18 years) were single at the time of the research. For the adults the following was found:

The groups do not appear to differ greatly, although Kalingalinga has more divorced people than Roma N’gome and Roma N’gome instead has more widowed people. Previously it was seen that the male to female ratio for the age group 25-49 differed from the rest of the group, the marital status of this age group gives us the following:

Comparing this to the whole population we can see that there are more married and less single people in this group. But more importantly we can see that in the age group 25-49 there are more widowed people that for the adult population as a whole, particularly in Roma N’gome. This may in part explain the male to female ratios that were seen earlier.

The above graphs focussed on all the adults in the households, both the respondent (PLHIV on ART) and the other adults in their households. It may also prove interesting to focus only on the respondents, namely the PLHIV on ART who were asked to take part in this research. When looking at the respondents (PLHIV on ART) in this research 39.1% is married and 31.1% is widowed. The percentage of people who are widowed amongst the respondents is almost twice as high in Roma N’gome (43.9%) than in Kalingalinga (23.4%), and while only 1.8% of the respondents in Roma N’gome is divorced this is 12.8% in Kalingalinga. The percentage of respondents that are single is also much higher in Kalingalinga (20.2%) than in Roma N’gome (5.3%).
**Household situation of children**

The majority of the children, 88.9%, is living with at least one biological parent. In Roma N'gombe 34.6% of the children live with both their biological parents, this is 47.7% in Kalingalinga. While just over half of the children in Roma N'gombe live with only their mother in Kalingalinga this is one third. 9.1% of the children in Kalingalinga live with only their biological father compared to 2.3% in Roma N'gombe.

The majority of the children live in households that are headed by one of their parents (71.8%) while just below 12% of the children live in households that are headed by one of their grandparents. In Roma N'gombe there are almost twice as many households headed by grandparents (15.2%) compared to Kalingalinga (8.2%).

In total 139 children reported that they were not living with their father. A total of 107 children from the 139 children reported that the reason they were not living with their father was because their father had passed away.

Far less children were not living with their mother, 44 in total reported not to be living with their mother out of which 29 had passed away. This means that more than 53% of all the children were no longer living with their father and 41% of the children have lost their father. Just under 17% of the children no longer lives with their mother out of which 11.1% have lost their mother.

In total 118 children (45.6%) of all children can be categorised as orphans. The majority of these are paternal orphans, and 23% are double or virtual52 double orphans.

![Orphans](image)

**Figure 5.4: Orphan status of children**

From the total 118 children who were found to be orphans 60.2% live in Roma N'gombe. 56.8% of all the children in Roma N’gombe were found to be orphaned compared to 35.1% in Kalingalinga. Statistically children in the Roma N'gombe research group are more likely to be orphans than children in Kalingalinga (p<0.000)53.

Knowing that there are more women than men infected with HIV it appears to be strange that there are more paternal than maternal orphans. Out of all the children who have lost one or two parents 89.4% in Kalingalinga and 97.2% in Roma N’gombe has lost their father while respectively 38.3% and 21.1% has lost their mother. Zambia is largely matrilineal and this may explain part of the above discrepancy. After the death of a child’s father children will often stay with their mother, while if the mother dies first the children are far less likely to stay with the father. After the death of a child’s mother, irrespective of whether or not the father is still alive, children are often sent away to other relatives. Children who have lost their mother are often sent to their grandparents in rural areas, thus moving away from the study area. Another factor that could be at play here is that men are disproportionately accessing ART less compared to women. Additionally, men are starting ART, on average, in a

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52 A virtual double orphan is a child whose parents may be alive but neither the child nor the guardians have any idea of the parents’ whereabouts, and no form of support whatsoever is provided to the child or their recipient household.

53 Based on Chi-square test.
more advanced stage of HIV infection (Cornell et al., 2009a; 2009b; 2012; Stringer et al., 2006; Hawkins, 2011; Taylor-Smith et al., 2010; Mills et al., 2011; Kip et al 2010), have lower survival rates than women (Cornell et al. 2009b; Muhula, 2012, Druyts et al. 2013, Mills et al., 2011, Geng et al., 2010), are more likely to interrupt treatment, and are more frequently seen to be lost to follow-up (LTFU) to ART (Kranzer et al. 2010; Ochieng-Ooko et al. 2010; Cornell, 2011, Mills et al. 2011).

### Adults and Education

Looking at the highest achieved level of education for adults it was found that 71.9% had completed at least primary school. This percentage was slightly lower in Roma N’gome (64.6%) and slightly higher in Kalingalinga (76.6%). The Zambian education system has three levels, namely: Primary (grades one to seven), Junior Secondary (grades eight to nine), and Upper Secondary (grades ten to twelve). There are three main exam years that determine whether one can pass onto the next level or not, these are in grades seven, nine, and twelve. When looking at the education levels of adults (18 and above) in Roma N’gome and Kalingalinga these three points clearly stood out. There is a difference in education levels obtained between Roma N’gome and Kalingalinga. This has been portrayed below:

![Highest level of education achieved (adults)](image)

**Figure 5.5: Highest level of education achieved by all adults, in Roma N’gome and Kalingalinga**

From the figure above it can be seen that there are more adults in Roma N’gome (91.8%) that have some form of education than in Kalingalinga (84.1%). However in terms of level of education it can be seen that adults in Kalingalinga who have attended school have completed higher levels of education than adults in Roma N’gome. The level of education in Kalingalinga was found to be higher than in Roma N’gome, this result is statistically significant.54

### Children and Education

Just under 80% of all the children aged 7-17 years is attending school on a full time basis and there is hardly any difference between the two areas. In the age group 7-14 years55 just over 85% of the children is attending school on a full time basis. Information was also collected regarding the costs of schooling. In Kalingalinga just under 6% of all the school going children are assisted with school related costs from sources outside the (extended) family or household, while just over 48% of the school going children in Roma N’gome is receiving support from external sources.56

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54 Based on a test.
55 In Zambia education is supposed to be free for all children of this age group and all children are expected to go to school, this is however often not the case. While officially school should be free for this age group this does not mean that there are no costs involved, for example: school uniforms, Parent-Teacher Association (PTA) contributions, books, etc.
56 External sources include a number of donors: Misereor, Churches Health Association Zambia (CHAZ), and Norwegian Church Aid. In addition, Roma N’gome is located nearby a school that caters for Orphans and Vulnerable Children (OVC) specifically, namely Kondwe Centre – Roma N’gome HBC and Kondwe Centre work together closely.
**Children and work**

Children below the age of seven generally are said to be too young to work. This is the case both in Roma N’gome (75.0%) and in Kalingalinga (66.0%). For both groups more than 90% of the children above seven are said to help around the house. Just a few children are said to be working for pay or profit: two children in Kalingalinga and three in Roma N’gome.

**5.2.2 Socio-economic indicators of households**

In the following section a closer look will be taken at the socio-economic situation of the studied households.

**Housing**

People who own the house that they are living in are less vulnerable than people who are renting. Not only do they not have to spend part of their income on rent, the money they do spend on their homes in a sense remains within their resource pool; home improvements will benefit the family directly. In addition these households run a much lower risk of having to move or being evicted. House ownership may also be a form of income for the household; some of the respondents reported that they rented out part of their property.

Just over 46.4% of the households owns the house that they live in. This is almost equal between the groups where 47.9% of the households in Kalingalinga owns the house they live in compared to 43.9% in Roma N’gome.

The rent in Kalingalinga is higher than it is in Roma N’gome. This is not surprising seeing that Kalingalinga is more developed than Roma N’gome. The following table describes the differences in rent:

<table>
<thead>
<tr>
<th></th>
<th>Roma N’gome</th>
<th>Kalingalinga</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>25th percentile (Q1)</td>
<td>ZMK 100,000.00 (~€ 15)</td>
<td>ZMK 180,000.00 (~€28)</td>
<td>ZMK 140,000.00 (~€ 22)</td>
</tr>
<tr>
<td>Median</td>
<td>ZMK 150,000.00 (~€ 23)</td>
<td>ZMK 300,000.00 (~€46)</td>
<td>ZMK 200,000.00 (~€ 31)</td>
</tr>
<tr>
<td>75th percentile (Q3)</td>
<td>ZMK 230,000.00 (~€ 35)</td>
<td>ZMK 380,000.00 (~€58)</td>
<td>ZMK 350,000.00 (~€ 54)</td>
</tr>
<tr>
<td>Mean</td>
<td>ZMK 205,483.90 (~€ 32)</td>
<td>ZMK 282,173.90 (~€ 43)</td>
<td>ZMK 251,298.70 (~€39)</td>
</tr>
</tbody>
</table>

*Table 5.8: Monthly cost of housing in Kwacha and Euro*

In terms of water and electricity access Kalingalinga again proves to be a more developed location to live in than Roma N’gome.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Roma N’gome</th>
<th>Kalingalinga</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electricity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>55.6%</td>
<td>38.6%</td>
<td>66.0%</td>
</tr>
<tr>
<td>No</td>
<td>44.4%</td>
<td>61.4%</td>
<td>34.0%</td>
</tr>
<tr>
<td>Water</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Running (piped) water in the house</td>
<td>11.3%</td>
<td>3.5%</td>
<td>16.0%</td>
</tr>
<tr>
<td>Running (piped) water to the yard/plot</td>
<td>20.5%</td>
<td>0.0%</td>
<td>33.0%</td>
</tr>
<tr>
<td>Public tap</td>
<td>62.3%</td>
<td>86.0%</td>
<td>47.9%</td>
</tr>
<tr>
<td>Other</td>
<td>6.0%</td>
<td>10.5%</td>
<td>3.2%</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

*Table 5.9: Households access to electricity and water in Roma N’gome and Kalingalinga*

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**57** Exchange rate 1 euro = 6,500.00 Zambian Kwacha
62.3% of all the households are dependent on a public tap for their water supply. However, taking a closer look it can be seen that this is the case for less than half of the households in Kalingalinga compared to 85.6% of the households in Roma N’gombe. In Kalingalinga 16.0% of the households has running water in their homes while only 3.5% of the households in Roma N’gombe has such a “luxury”. An additional 33.0% of the people in Kalingalinga has running water to their yard/plot compared to not a single household in Roma N’gombe. As such, almost 50% of the households in Kalingalinga has running piped water within their near vicinity (in the home or their yard/plot) while this is the case in just 3.5% households in Roma N’gombe. A similar situation can be seen in terms of access to electricity where 55.6% of the people have access to electricity; of which 66.0% of the households live in Kalingalinga and just 38.6% live in Roma N’gombe. In terms of electricity 73.8% of the people who have access to electricity live in Kalingalinga.

Food

Food intake and food security is often a problem for people with low incomes. It is an additional problem for people on ART seeing that a proper diet enhances the effectiveness of the ART. In addition, a lot of people on ART find that the medication makes them hungry.

Respondents were asked about their food intake both in terms of frequency and in types of food. From all respondents 44.4% reported to have eaten three meals the previous day, 39.1% ate only two meals the previous day, and 15.9% ate just one meal the previous day.

In Kalingalinga 50% of the respondents ate three meals the previous day compared to 25.1% in Roma N’gombe. The percentage of respondents who ate two meals the previous day is almost the same in both locations whilst the percentage of people who ate just one meal the previous day is higher in Roma N’gombe (24.6%) than in Kalingalinga (10.6%).

Looking more closely at the type of food that people eat we can see that types of food at breakfast differ from dinner and lunch which often are similar. Just under 60% of the respondents who reported that they ate breakfast yesterday report that they had a drink (most often tea) with (plain) bread, and around 20% report they had porridge58 for breakfast. This trend does not differ between the two groups.

For lunch and dinner people typically eat Nshima with some form of relish59. Respondents were asked what they had for lunch and dinner the previous day. The answers that were provided were coded and this resulted into three main groups and one “other” category. The three main groups that were created were:

- staple food (nshima or rice) and at least one type of relish that contained animal products (meat such as beef, chicken, fish, kapenta60, or other animal products such as eggs);
- staple food (nshima or rice) and at least one type of relish that contained non-animal protein (such as groundnuts, soya, etc)
- staple food (nshima or rice) and at least one type of vegetable relish (such as cabbage, rape, pumpkin leaves, etc)

58 In Zambia the main staple food is called Nshima which is made of maize meal (in Zambia called mealie meal). The maize flour is boiled with water to create a type of porridge, at this stage it can be eaten as porridge or more maize flour can be added to create Nshima. Porridge is often eaten by children or for breakfast.
59 Side dishes are referred to as relish. Nshima is often eaten with relish, in an ideal situation there are at least two side dishes: a protein source such as meat, poultry, fish, or groundnuts; and a dish made of vegetables, such as chibwabwa (pumpkin leaves), cabbage, or spinach leaves.
60 Kapenta: The Tanganyika sardine, is known as Kapenta in Zambia.
Looking at the group as a whole it can be seen that 41.4% of the respondents reported to have had staple food and at least one type of relish that contained animal products for lunch and/or dinner. Next 34.8% of the respondents reported to have had staple food and relish containing only vegetables for lunch and/or dinner.

Splitting the group up according to geographical location provides a different picture. This can be seen in the following chart:

![Chart showing lunch and dinner food intake in Roma N'gombe and Kalingalinga.]

Figure 5.6: Nutrition – Food intake for lunch and dinner in Roma N'gombe and Kalingalinga.

In the figure it can be seen that the percentage of people in Kalingalinga who are able to have meat in their diet is higher than in Roma N'gombe. In Roma N'gombe around 50% of all meals consist of only staple food and vegetables. A balanced diet for PLHIV is of vital importance for their health. The above suggests that people in Roma N'gombe are struggling to achieve such a well-balanced diet. Not only are people in Roma N'gombe eating less meals per day, compared to Kalingalinga, they appear to also have less well balanced diets. The most likely reason for this difference is economical.

Food shortages are a frequent occurrence for poor households in Zambia. These can occur when salaries are paid late, work cannot be found, school fees need to be paid, and even seasonal shortages occur. For the total group it was found that 78.2% of the households experienced food shortage at some point. When comparing the two geographical locations it can be seen that almost all households in Roma N'gombe (93.0%) are experiencing food shortages compared to 69.2% in Kalingalinga.

Just under half (48.3%) of the households reported that the food shortages they experienced coincided with a specific period in the month. Respondents gave a number of explanations for this. This included: low salaries that are not enough to get people through the month; salaries are not paid on time; households that rent out part of their house have tenants paying the rent late. 22.4% reported that they permanently suffered from food shortages, reasons given included: no permanent source of income and piece work is hard to find; unable to work and as such dependent on other people for food. Just over 10% of the respondents explained that their food shortages coincided with the rainy season and just under 5% reported that food shortages occurred when they needed to pay school fees.

61 For prices of food and commodities in Zambia see the basic needs basket in Appendix 2: Basic Needs Basket.
62 Regarding food shortages, all respondents were asked: “Does your household ever experience food shortages?” If the answer was “yes” people were then asked: “Is there a specific period in the year or in the month when you experience food shortages?” Food shortages as such were not defined in terms of a specific period or number of meals per day but rather on the lived experiences of the respondents.
In Roma N’gombe more people (54.7%) reported to experience food shortages at a specific point in the month compared to 42.9% in Kalingalinga. Instead almost 20% of the people in Kalingalinga reported that they experienced food shortages during the rainy season, while none of the people in Roma N’gombe reported this.

The majority (90.7%) of the households reports that most of the food they consume is bought. In Kalingalinga this is 94.7% of the households and in Roma N’gombe this is 84.2%. In Roma N’gombe 10.5% of the interviewed households were dependent on well-wishers while only one household in Kalingalinga reported this as their main source of food.

Production
Agriculture, including husbandry, can reduce food insecurity. Food production is possible in urban areas, however it is not frequently done in the research areas. Less than 10% of all households said that they produced food: 8.8% of the households in Roma N’gombe and 7.5% of the households in Kalingalinga. The type of food that was produced by these households included: maize, vegetables (such as tomatoes, rape, etc), groundnuts, and sweet potatoes.

In terms of husbandry less than 10% of all households owned poultry or cattle: just under 10% of the households in Kalingalinga and 3.5% of the households in Roma N’gombe.

Energy
In total 60.9% of the households reported that charcoal was the main source of energy that they used for cooking and 38.4% reported electricity as their main source of energy for cooking. When comparing this for Roma N’gombe and Kalingalinga it can be seen that a higher percentage of households in Kalingalinga (50%) compared to 19.3% in Roma N’gombe reports electricity as their main source of energy for cooking. As mentioned previously, more households in Kalingalinga have access to electricity than in Roma N’gombe.

Assistance
There are many types of assistance that households can receive, this includes: nutritional support, material support, and financial support. As seen previously a large proportion of the children going to school in Roma N’gombe are being supported through external sources. When looking at all assistance received by households it can be seen that just over 50% of all households receive assistance from outside the household. Upon closer inspection it can be seen that there are differences between the two areas studied. In Kalingalinga 31.9% of the households studied receive assistance from outside the household while in Roma N’gombe 80.7% of the households receive assistance from outside the household. This result is statistically significant. Respondents were also asked what the nature of the assistance was and from whom they received this assistance. Only a small proportion of the assistance that people received came from their own family. The other assistance came from external sources. These sources included: international organisations, NGO’s, and the church.

Adults and work
For each household member (18 years or above) information was gathered on what type of work they did. In the whole group less than 15% was formally employed and 26.8% was informally employed, 21.5% was running some sort of business, and 8.4% said they did piecework. Being formally employed often means higher salaries and less at risk to fluctuating incomes. Informal employment to some degree also reduces the risk of fluctuating salaries but makes people vulnerable as they are in no way formally protected and a minimum wage is not guaranteed. Running a business can be profitable. However there are a large number of factors that can

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63 Well-wishers is a term used in Zambia for non-family members who in some way support or provide commodities. This can refer to NGO’s, neighbours, church members, etc.

64 Based on a chi2 test (p<0.000)
influence the success and as such also the profit it may bring in. Finally piecework is the least favourable situation as there is no guarantee work will be found on any given day and wages are often low.

If we compare the situation in Kalingalinga to the situation in Roma N'gombe the following is found:

![Employment status adults (in percentages)](image)

In the figure above we can see that on the whole more people in Kalingalinga are working for some form of income; there is a higher percentage of people that are both formally and informally employed and more people run their own business. The percentage of people dependent on piecework is the same for both locations. Kalingalinga also has more adults who are not working because they are still in school than Roma N'gombe. While Roma N'gombe has a much larger group of people who do not work for pay or profit but instead look after the house and household. The large difference between Roma N'gombe and Kalingalinga in terms of the amount of people that report to only do house chores may have to do with the difference in job opportunities between the two areas. While people in Roma N'gombe may wish to be working for payment/profit they may be unable to find any work. In Roma N'gombe 41.9% of the adults who report that they are not working for payment/profit but doing only house chores are the biological children of the head of the household and 32.3% are the spouses.

While it is interesting to look at the type of jobs people are doing it is important to also look at the household income. Looking at the household income the following was found:

<table>
<thead>
<tr>
<th></th>
<th>Roma N'gombe</th>
<th>Kalingalinga</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>25(^{th}) percentile (Q1)</td>
<td>ZMK 300,000.00 (~€ 46)</td>
<td>ZMK 400,000.00 (~€62)</td>
<td>ZMK 300,000.00 (~€ 46)</td>
</tr>
<tr>
<td>Median</td>
<td>ZMK 500,000.00 (~€ 77)</td>
<td>ZMK 644,500.00 (~€99)</td>
<td>ZMK 600,000.00 (~€ 92)</td>
</tr>
<tr>
<td>75(^{th}) percentile (Q3)</td>
<td>ZMK 700,000.00 (~€ 108)</td>
<td>ZMK 900,000.00 (~€139)</td>
<td>ZMK 800,000.00 (~€ 123)</td>
</tr>
<tr>
<td>Mean</td>
<td>ZMK 534,792.50 (~€ 82)</td>
<td>ZMK 730,361.70 (~€112)</td>
<td>ZMK 659,850.30 (~€102)</td>
</tr>
<tr>
<td>Person/day(^65)</td>
<td>ZMK 3,819.95 (~€ 0.59)</td>
<td>ZMK 6,521.09 (~€ 1.00)</td>
<td>ZMK 5,355.93 (~€ 0.82)</td>
</tr>
</tbody>
</table>

\(^{65}\) The average income per person per day was calculated as follows: mean income divided by the average household size for the group and this was divided by 28 (4 weeks). The average household size is 4.4 for the whole group, 5.0 in Roma N'gombe, and 4.0 in Kalingalinga.

\(^{66}\) Exchange rate 1 euro = 6,500.00 Zambian Kwacha
The following table shows the percentage of households that is above or below a poverty line of $1 per person per day and $1.25 per person per day.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Roma N’gcombe</th>
<th>Kalingalinga</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poverty line $1 per person per day</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Above</td>
<td>42.2%</td>
<td>17.0%</td>
<td>56.4%</td>
</tr>
<tr>
<td>Below</td>
<td>57.8%</td>
<td>83.0%</td>
<td>43.6%</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Poverty line $1.25 per person per day</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Above</td>
<td>34.7%</td>
<td>13.2%</td>
<td>46.8%</td>
</tr>
<tr>
<td>Below</td>
<td>65.3%</td>
<td>86.8%</td>
<td>53.2%</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Table 5.11: Percentage of households that is above or below a poverty line of respectively 1 or 1.25 dollars per person per day

From the above it can be seen that while only 17% of the households in Roma N’gcombe have an income of more than $1 per person per day this is 56.4% in Kalingalinga. Both for a poverty line of $1 and $1.25 per person per day is the percentage of households above these poverty lines more than three times as high in Kalingalinga compared to Roma N’gcombe.

Assets
Whether or not households own certain assets or not and the amount of each asset they own can give an indication of the socio-economic situation of the households. Households were asked whether they owned certain assets and, if yes, how many of the specific item they owned.

![Percentage of Households that own specific asset](image)

Figure 5.8: Assets owned by household in Kalingalinga and Roma N’gcombe, percentage of households that own specific asset

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67 Exchange rate 1 dollar = 5,270.00 Zambian Kwacha, which was the exchange rate on the 1st April 2012.
68 The average income per person per day was calculated as follows: income was first converted to dollars, then divided by the number of people in the household and this was divided by 28 (4 weeks).
A higher percentage of the households in Kalingalinga, compared to Roma N’gombe, reported that they owned the discussed assets. The number of assets per household, was also calculated and here too this was higher in Kalingalinga when compared to Roma N’gombe.

In terms of tools a similar pattern can be found where more households in Kalingalinga own tools compared to Roma N’gombe. Additionally, there are more tools per household in Kalingalinga.

**Summary conclusions**

This section looked at the socio-economic status of PLHIV and their household in Roma N’gombe and Kalingalinga. From the above results it can be seen that the socio-economic situation in Kalingalinga is better than that in Roma N’gombe.

Home ownership is slightly higher in Kalingalinga than in Roma N’gombe. While more than half of the respondents lived in rented houses in both areas it is also important to get a better understanding of this. In Roma N’gombe the general rental prices were lower than that of Kalingalinga. This difference is due to the area of Roma N’gombe being poorer than that of Kalingalinga. Not only is Kalingalinga located in a better area, the difference is also reflected in the quality of the houses. In Roma N’gombe just 38.6% of the houses have access to electricity, compared to 66% in Kalingalinga. In terms of water only 3.5% of the houses in Roma N’gombe have running (piped) water in either their house or yard/plot compared to 49% of the houses in Kalingalinga.

Looking at the source of energy that people used for cooking the above noted difference in access to electricity is reflected. 50% of the households in Kalingalinga used electricity as their main energy source for cooking, compared to 19.3% in Roma N’gombe.

Looking at the food intake of the respondents living in Kalingalinga it can again be seen that the situation is better than that of the respondents living in Roma N’gombe. In Kalingalinga 50% of the respondents ate three meals the previous day compared to 25.1% in Roma N’gombe. The percentage of respondents who ate two meals the previous day is almost the same in both locations whilst the percentage of people who ate just one meal the previous day is higher in Roma N’gombe (24.6%) than in Kalingalinga (10.6%).

The type and quality of the meals eaten by respondents in Kalingalinga is also higher than that of the people in Roma N’gombe. In Roma N’gombe around 50% of all meals consist of only staple food and vegetables. The percentage of people in Kalingalinga who are able to have meat or some form of protein in their diet is higher than in Roma N’gombe. People in Roma N’gombe are eating fewer and less balanced meals per day, compared to Kalingalinga.

Finally, also household food security also appears to be more vulnerable in Roma N’gombe than in Kalingalinga. Almost all households in Roma N’gombe (93.0%) are experiencing food shortages compared to 69.2% in Kalingalinga.

In Kalingalinga 31.9% of the households studied receive assistance from outside the household while in Roma N’gombe 80.7% of the households receive assistance from outside the household. The majority of this assistance came from external sources, including: international organisations, NGO’s, and the church.

In terms of income and employment a difference between Roma N’gombe and Kalingalinga also exists. Not only are there more people working for payment/profit in Kalingalinga, the type of employment people have in Kalingalinga is also more secure than in Roma N’gombe. In Roma N’gombe just under 30% of all the adults are said not to be working for payment/profit and only doing house chores. Kalingalinga has more household where

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69 Tools discussed included: plough, knitting machine, wheelbarrow, hoe, shovel, axe, peanut butter machine, small tools (e.g. hammer, screwdriver, etc.), and grinder.
there is more than one bread winner when compared to Roma N’gombe. Additionally, the average monthly household income for people living in Kalingalinga is higher than for those living in Roma N’gombe. Households in Roma N’gombe are on average bigger than households in Kalingalinga yet the average monthly household income is lower in Roma N’gombe than in Kalingalinga. Only 17% of the households in Roma N’gombe have an income of more than $1 per person per day compared to 56.4% in Kalingalinga. Both for a poverty line of $1 and $1.25 per person per day the percentage of households above these poverty lines is more than three times as high in Kalingalinga compared to Roma N’gombe.

Finally in terms of household assets a higher percentage of the households in Kalingalinga, compared to Roma N’gombe, reported that they owned the discussed assets. The number of assets per household, was also calculated and here too this was higher in Kalingalinga when compared to Roma N’gombe. In terms of tools a similar pattern was found where more households in Kalingalinga owned tools compared to Roma N’gombe. Additionally, there are more tools per household in Kalingalinga.

5.2.3 Health and well-being
In order to get a better understanding about people’s health status respondents were also asked to answer a number of questions regarding their (self-reported) mental and physical health. The results of these are discussed in this section.

**General Health**
Regarding general health people were asked how in general they viewed their health and were given a number of categories they could choose from. The categories that were available were: Excellent, Very Good, Good, Fair, and Poor. Placing the results into a bar chart, for the two sites, provides us with the following:

![General health in percentages](chart)

**Figure 5.9: Self-reported general health of respondents (PLHIV on ART)**

From the above we can see that it appears that people in Roma N’gombe have a more positive view of their health status than people in Kalingalinga. While more than 90% of the people in Roma N’gombe view their health as good or better this is the case for slightly less than two thirds of the people in Kalingalinga where 27.3% views their health as fair or poor. The difference was found to be statistically significant (p<0.000).^70^

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^70^ Based on Chi-square test.
People were also asked to grade their life on a scale from one to ten, where ten was the highest and one the lowest. Here the mean score for Roma N’gombe was 8.1 and for 6.9 for Kalingalinga (the difference was found to be statistically significant p<0.010).  

The above discussed questions are related to respondents’ general view of their overall health and life. In the next sections respondents’ physical health and emotional health will be discussed. The questions used in the next section all have a time frame that respondents should refer to.

**Physical health**

Regarding respondents physical health a number of questions were asked. The first question discusses how, on a typical day, people’s health may have limited them in performing certain activities. The first part of the questions discusses to what degree the respondents’ health has limited them in doing light/easy activities while the second part looks at heavy/hard activities. Answer categories included “Yes, limited a lot”, “Yes, limited a little”, “No, not limited at all”.

From all respondents 60.3% reported that their health had not limited them at all in light/easy activities while 35.8% of all respondents reported to have been not been limited at all in heavy/hard activities. Comparing the two locations it was seen that Kalingalinga had a higher percentage of respondents (67.0%) who reported to have not been limited at all in light/easy activities compared to Roma N’gombe (49.1%). In terms of heavy/hard activities the percentage of people reporting that they were not limited at all was approximately the same in both locations. For both locations, the percentage of people who reported not to be affected at all by their health in both light/easy and heavy/hard activities was around 35%.

The next set of questions looks at how work or other regular activities may have been affected by people’s physical health. The questions ask people to indicate how often in the last four weeks their physical health has caused them to (1) accomplish less and (2) has limited them in the kind of work or activities they perform. The answer categories for these questions were: “all of the time”, “most of the time”, “some of the time”, “a little of the time”, and “none of the time”. For both questions, and in both areas studied, the results were more or less the same. Just under 40% of all respondents reported that their physical health had limited them none of the time. From the people who reported that their physical health had limited them in their activities sometime over the last 4 weeks between 70-80% reported that they were limited “a little of the time” or “some of the time”.

People were also asked to what degree they were hindered in performing their work due to pain. For this question the answer categories included: “not at all”, “a little bit”, “moderately”, “quite a bit”, “extremely”. In both Roma N’gombe and Kalingalinga 40.4% of the respondents reported that in the last four weeks pain never interfered with their work/activities. In Roma N’gombe 33.3% of the respondents reported that pain interfered with their work a little bit compared to 20.2% in Kalingalinga. For both areas the percentage of respondents who were moderately hindered by pain was around 20%. The percentage of people who reported to be hindered by pain quite a bit and extremely was higher for both in Kalingalinga (respectively 10.6% and 7.5%) compared to Roma N’gombe (respectively 7% and 0%).

**Mental health**

Respondents were also asked to answer a number of questions regarding their mental health. The results of these questions will be discussed in this section. This will be done for the group as a whole and also comparing the two locations.

---

71 Based on Chi-square test.
72 Light/easy activities include things such as moving a table, sweeping, or hanging up washed clothes.
73 Heavy/hard activities include things such as climbing up a steep hill, walking large distances, carrying water, breaking rocks, or collecting firewood.
This first question discussed to what degree emotional problems (such as feeling depressed or anxious) had caused respondents to a) accomplish less than they would have wanted to and b) limited them in the kind of work or activities they were doing. Available answer options to these questions were: all of the time, most of the time, some of the time, a little of the time, and none of the time.

Just over one third of the respondents reported that they never accomplished less than they wanted to or were limited in their kind of work or activities they were doing due to emotional problems. A small percentage of respondents (2.6%–3.3%) reported that, for both questions, emotional problems hindered them all of the time. While the majority of the respondents were hindered in their activities to some degree due to emotional problems this was reported to be only some of the time or a little of the time. Around 85% of all respondents were either hindered some of the time, a little of the time, or none of the time, for both questions.

Taking a closer look at the data it can be seen that when comparing the data for Kalingalinga and Roma N'gombe there are a few differences. While less than 10% of the people in Roma N'gombe accomplished less or were limited in their work due to emotional problems this is around 20% in Kalingalinga. Roma N'gombe also has a slightly higher percentage of people who are hindered none of the time than respondents in Kalingalinga.

The above questions focus on the productivity of respondents and how this may be hindered by emotional problems. While people may not feel that their work is hindered by emotional problems this does not mean that they may not be suffering in silence while still continue with their daily activities. The next three questions were devised to provide an insight into how people may be feeling. All three questions use the same answer categories as were used in the previous two questions and all ask people to what degree they have had or felt in a certain way in the last four weeks. The first question asks people how often they have felt calm and peaceful, the second questions how often they have had a lot of energy, and the third question how often they have felt downhearted and depressed.

![Mental health chart]

**Figure 5.10: Self-reported mental health scores in Roma N'gombe and Kalingalinga**

From the above figure we can see that the general trend is the same for both sites. However respondents in Roma N'gombe appear to generally respond more positively than respondents in Kalingalinga. While more than 70% of the respondents in Roma N'gombe said that they felt calm and peaceful all the time this was only the case for just over 40% in Kalingalinga. The same can be seen for the question whether or not people had a lot of energy in the past four weeks, where in Roma N'gombe around 65% of the respondents said they had a lot of
energy all of the time, compared to just under 40% in Kalingalinga. The last question regarding whether people ever felt downhearted or depressed in the last four weeks was answered as follows: just under 65% of the respondents in Kalingalinga and just over 50% of the respondents in Roma N’gome said they had felt downhearted or depressed a little or none of the time in the last four weeks; just over 15% in Kaligalinga and just over 35% in Roma N’gome had felt downhearted or depressed some of the time in the last four weeks; and finally just under 20% in Kalingalinga and just over 10% in Roma N’gome had felt downhearted or depressed all or some of the time over the last four weeks.

Physical and Mental Health

Finally people were also asked to reflect on how either their physical health or their emotional problems had impacted their social activities. 58% of all respondents reported that their social activities had been impacted to varying degrees over the past four weeks by their physical and/or emotional problems.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Roma N’gome</th>
<th>Kalingalinga</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>42.0%</td>
<td>42.1%</td>
<td>41.9%</td>
</tr>
<tr>
<td>A little bit</td>
<td>28.0%</td>
<td>29.8%</td>
<td>26.9%</td>
</tr>
<tr>
<td>Moderately</td>
<td>14.0%</td>
<td>17.5%</td>
<td>11.8%</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>12.0%</td>
<td>10.5%</td>
<td>12.9%</td>
</tr>
<tr>
<td>Extremely</td>
<td>4.0%</td>
<td>0.0%</td>
<td>6.5%</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Table 5.12: Physical health/Emotional problems interfered with social activities in the past four weeks

There appears to be little difference between the responses in the two areas, although it should be noted that there are no respondents in Roma N’gome who feel they are hindered extremely in their social activities because of their physical health or their emotional problems.

On first sight it appears that the group of respondents in Roma N’gome reports a more positive picture regarding their physical and mental health than the respondents in Kalingalinga. However, this conclusion should not be drawn too easily. The group of respondents in Roma N’gome was already selected in 2010 and between 2010 and 2012 has almost been reduced by half. As such, the group is different in a number of ways which may impact the outcomes. The first being the duration of ART. People who have been on ART for a longer period of time may have become accustomed to their medication better and as such may also feel their health to be better. The second factor that should be taken into consideration is the characteristics of the non-response group. People who may now no longer be alive but were alive in 2010 may have had a far worse health status than is now found for the group in 2012. People who moved could have done so for better job opportunities, however could also have done this for less positive reasons. One of the interviewers explains: “Sometimes we lose track of people, when we go visit them we find they moved. When we ask the neighbours where they went they tell us: “These ones moved in the night, we don’t know where they are now”. Here people move often and when they move in the night they often don’t tell anyone out of fear that maybe someone who they still owe some money will find them”. There clearly exist numerous reasons why people may not be around to be interviewed anymore in 2012 and this could cause some bias, hence it should be taken into consideration.

Summary conclusion

This section looked at the physical, emotional, and general perceived health of PLHIV in Roma N’gome and Kalingalinga. From the above results it can be seen that the physical health scores in Roma N’gome and Kalingalinga are very similar. In terms of self-perceived general health scores and emotional well-being people in Roma N’gome score higher than people in Kalingalinga.

The differences between Kalingalinga and Roma N’gome regarding physical health, emotional health, and general perceived health is shown in table 5.13. For all results in this table the higher the average or median is
found to be the higher the mental or physical well-being is. In table 5.13 it can be seen that for general self-reported well-being the mean and median is higher in Roma N’gome than in Kalingalinga. For emotional well-being a similar result was found. Finally, for physical well-being it can be seen that there is little difference between Kalingalinga and Roma N’gome.

<table>
<thead>
<tr>
<th></th>
<th>Roma N’gome</th>
<th>Kalingalinga</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Median</td>
</tr>
<tr>
<td><strong>General self-reported well-being</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In general, would you say your health is: 1. poor, 2. Fair, 3. Good, 4. Very good, 5. Excellent</td>
<td>3.79</td>
<td>4 Very good</td>
</tr>
<tr>
<td>If you could give your life a grade between 1 and 10, where 10 is the highest and 1 is the lowest, what grade would you give it?</td>
<td>8.14</td>
<td>9</td>
</tr>
<tr>
<td><strong>Emotional well-being</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>During the last four weeks how much of the time: have you felt calm and peaceful</td>
<td>3.98</td>
<td>4 Most of the time</td>
</tr>
<tr>
<td>did you have a lot of energy</td>
<td>3.82</td>
<td>4 Most of the time</td>
</tr>
<tr>
<td>did you feel downhearted and depressed</td>
<td>3.75</td>
<td>4 A little of the time</td>
</tr>
<tr>
<td><strong>Physical health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>On a typical day does your health limit you (1) a lot, (2) a little, or (3) not at all in the following activities: light/easy activities, such as moving a table, sweeping, or hanging up washed clothes</td>
<td>2.42</td>
<td>2 Yes, limited a little</td>
</tr>
<tr>
<td>heavy/hard activities, such as climbing up a steep hill, walking large distances, carrying water, breaking rocks, or collecting firewood</td>
<td>2.19</td>
<td>2 Yes, limited a little</td>
</tr>
</tbody>
</table>

Table 5.13: Comparing general, physical, and mental health results for Roma N’gome and Kalingalinga

From the above it can be seen that people in Roma N’gome have a more positive outlook on their general health and life than people in Kalingalinga. In addition, people in Roma N’gome score higher on the questions regarding their mental health.

Mental health scores and a positive outlook on life may be stimulated through accepting ones status and “living positively” (with HIV). Many people attend support group meetings and receive support and counseling in order to come to terms with their status. The presence of a strong Home Based Care project (HBC) can play a vital role in this.

Comparing Roma N’gome and Kalingalinga a difference can be seen in the HBC project. Roma N’gome has a very active HBC project: it holds a number of monthly support group meetings (male/female/couples), holds trainings on livelihood strategies, and is open a minimum of four days a week for counseling sessions. Roma N’gome continues being open and holding meetings regardless of whether there is funding for this. In Kalingalinga sporadic support group meetings are held and the HBC opens its doors only when funding is available. As such, people in Roma N’gome can seek support far more easily than in Kalingalinga.

The relation between support, counseling, and positive living in relation to the mental health and attitudes of people is discussed more in depth in Chapter 8.
5.3 Conclusion

In this chapter a large number of general findings of this research were discussed, and data was provided to answer the following questions:

- What are the personal characteristics and socio-economic situation of individuals, and their households, receiving ART?

In the first section a number of characteristics and demographics were discussed, these included: mean age, sex distribution, orphan status of children, marital status, household composition, etc. In the second section a number of characteristics regarding the socio-economic situation of the respondents’ household were looked at, this included: housing situation, employment situation, income levels, food intake (frequency and type of food), energy, assets, etc. In the third section the respondents’ (self-reported) health status was discussed, this included both their physical and mental health. For all three sections both the groups as a whole were discussed as well as the two chosen locations separately and in comparison to each other. Differences in outcomes in the two locations occurred throughout the chapter.

General Findings

Characteristics of 663 individuals were collected from a total of 151 households. For the group as a whole there were more females than males and this difference is more apparent in Roma N'gombe than in Kalingalinga. The average household size in Roma N'gombe is significantly higher than in Kalingalinga.

The population pyramid for the researched population shows two visible gaps which would normally not be expected. The shape that was found has been predicted in other countries and attributed to the HIV pandemic. One of the gaps that was seen is in the age group 25-49 and the other in the age group 0-4. On closer inspection, of the first group, we can see that the male to female ratio for this group also differs strongly from the group as a whole: where the male to female ratio was 1:1.15 for the whole group, it is 1:1.5 for the 25-49 age group. This difference is even more dramatic when looking at the two geographic areas separately where there were 2.2 women per every man in Roma N'gombe and 1.3 women per man in Kalingalinga. In 2010, amongst the same households, there were 1.9 women per man in Roma N'gombe showing an increase in two years.

Marital status, for adults, between the two geographic areas didn't reveal much difference. However, when looking specifically at the age group 25-49 it could be seen that there is an increase in the number of widowed people, particularly, in Roma N'gombe. This may hold part of the explanation as to the male and female ratios. The marital status of the respondents (PLHIV on ART) was also looked at and this revealed that amongst this group the number of widows was also higher than was found for the adult population as a whole. In Roma N'gombe 43.9% of the respondents were widowed and in Kalingalinga this was 23.4%.

There were 259 children in the surveyed households, of these 118 (45.6%) can be categorised as orphans. The majority, 72%, of the children who were orphaned were paternal orphans. Roma N'gombe is home to 60.2% of all the orphans in this research. Children in Roma N'gombe have a higher chance of being an orphan than children in Kalingalinga.

The level of education for adults in Kalingalinga was found to be higher than in Roma N'gombe. A larger proportion of adults in Kalingalinga has completed their junior and upper secondary school compared to Roma N'gombe, in addition the percentage of people who have completed some form of higher education is more than four times as high in Kalingalinga. The number of children attending school in Roma N'gombe and in Kalingalinga is basically the same and 85% of all the children, in the age group 7-14 years, are attending school on a full time basis. It should be noted that 48% of the children in Roma N'gombe who are attending school are receiving assistance with school related costs, compared to only 6% in Kalingalinga. Households often also receive
assistance for other things, such as nutritional support. Households in Roma N’gombe not only receive more educational support but also other support: 80.7% of the households in Roma N’gombe reported that they received external support, compared to 31.9% in Kalingalinga.

The housing situation in Kalingalinga is better than in Roma N’gombe, this difference is reflected in the rental prices which are higher in Kalingalinga than in Roma N’gombe. The access to electricity in Kalingalinga is also higher than in Roma N’gombe, where 66.0% of the households in Kalingalinga has access to electricity compared to 38.6% in Roma N’gombe. The majority of the households in Roma N’gombe is dependent on a public tap for their water supply and hardly any households have a tap in their yard/plot or home (3.5%). In Kalingalinga only 47.9% of the households are dependent on a public tap and almost 50% has a tap in their yard/plot or home. The main source of energy for cooking was charcoal, 79.0% of the households in Roma N’gombe used charcoal and 50.0% in Kalingalinga. In Kalingalinga 50.0% of the households used electricity as their main source for cooking, compared to only 19.3% in Roma N’gombe.

Food intake in Kalingalinga, compared to Roma N’gombe, is better in both the frequency of meals and in the type of meals. In Kalingalinga 50% of the respondents reported that they ate three meals the previous day, compared to 25.1% in Roma N’gombe. In terms of the type of food it can be seen that people in Kalingalinga eat more meat and non-meat proteins than people in Roma N’gombe. Food shortages are also more frequent in Roma N’gombe, where 93.0% of the households report to experience food shortages, compared to 69.2% in Kalingalinga.

Agriculture, including animal husbandry, was hardly done in either location.

The percentage of people who are either informally or formally employed as well as people who run a small business is higher in Kalingalinga than in Roma N’gombe. There are also more people in Kalingalinga who are not working because they are still attending school than in Roma N’gombe. Instead Roma N’gombe has a much higher percentage (29.2%) of people whom are unemployed at all compared to Kalingalinga (3.6%). These differences in employment can also be seen in the differences in income levels which are higher in Kalingalinga than in Roma N’gombe. In terms of household assets a similar economic pattern was found where more households in Kalingalinga own certain assets compared to Roma N’gombe.

In terms of health and well-being a number of outcomes were found. People in Roma N’gombe give higher grades when asked to reflect on their lives and their general health compared to Kalingalinga. However, when looking at their more objective health outcomes it appears that their physical health status is comparable or less good than that of people in Kalingalinga. 67% of the people in Kalingalinga report that their health does not limit them at all in light/easy activities compared to 49.1% of the people in Roma N’gombe. In terms of heavy/hard activities the percentage is approximately the same. In terms of pain the percentage of people who were not hindered by pain at all was around 40%. However, for the remaining group of people who were hindered in their work due to pain it could be seen that this hindrance was more apparent in Kalingalinga than in Roma N’gombe. From the above we can see that while people in Roma N’gombe grade their life more positively and also report more positively on their health this is not reflected in their reported physical health.

The mental health of respondents was also discussed, both in terms of how this impacted their daily work and activities as well as how they felt. The data suggests that the percentage of people who are extremely hindered in their work and daily activities due to emotional problems is slightly higher in Kalingalinga (around 20%) compared to Roma N’gombe (around 10%). Mental health is not only important in terms of how it may impact someone’s productivity it also impacts someone general outlook on life and general well-being. People in Roma N’gombe generally appeared to have a more positive outlook than people in Kalingalinga. 70% of the respondents in Roma N’gombe reported that they felt calm and peaceful all or almost all of the time compared to 40% in Kalingalinga. Similarly 65% of the people in Roma N’gombe reported to have had a lot of energy all or almost all of the time in the last four weeks, compared to 40% in Kalingalinga. In terms of feeling downhearted or
depressed just 10% of the respondents in Roma Ngombo reported to have felt downhearted or depressed all or almost all of the time in the last four weeks, compared to 20% in Kalingalinga.

**Discussion**

The HIV epidemic clearly has had an impact in the population under study. Part of the visible impact may stem from a period before ART was available and is continuing to impact the population, however, while certain trends may be mitigated by ART it remains a question if they have been fully halted. From the data we can see that there is a feminisation of the HIV epidemic: there are more females than males (and this trend has continued from 2010 into 2012), the majority of the orphans here are paternal. While the situation appears to be more outspoken in Roma Ngombo, this feminisation is present in both locations.

This chapter has provided an overview of the characteristics of households and respondents in Roma Ngombo and Kalingalinga. Clearly Kalingalinga is the better place to live in terms of socio-economic factors and opportunities. In terms of assistance people in Roma Ngombo appear to receive more school assistance, nutritional support, and financial and material support. At the same time households in Kalingalinga appear to be doing better or the same as households in Roma Ngombo.

In terms of health the physical health of people in Kalingalinga appears to be slightly better in Kalingalinga than in Roma Ngombo. However, emotionally it appears that people in Roma Ngombo are doing better. They appear to be less emotionally hindered, generally feel better, and have a more positive outlook on life and their general health. As mentioned previously it should not be forgotten that the group of respondents in Roma Ngombo was already selected in 2010 and not all respondents were available for interviewing in 2012, so this may have influenced the findings.

The positive outlook of people in Roma Ngombo where one would perhaps expect a more negative outcome, in comparison to Kalingalinga, considering the other conclusions may not be completely unsurprising. One possible explanation may actually lie in the additional support, not so much in material support, but in terms of social support. Roma Ngombo HBC may often lack funds, just like Kalingalinga HBC, but is more active and successful at organising other funds as well as organising activities. There appears to be a difference in leadership and commitment between the two HBC projects. The economic differences in households in Roma Ngombo area are less apparent than in the Kalingalinga area. Perhaps the idea of all facing the same difficulties and doing this together may provide a more positive outcome than in a situation wherein differences between people are larger and problems are faced ‘alone’, like in Kalingalinga.
Chapter 6 – Roma N’gombe 2010-2012

6.1 Introduction

This chapter will focus on a group of PLHIV on ART in Roma N’gombe that were interviewed in 2010 and again in 2012. Trends that were found in 2010 will be explored and further analysed. By comparing data from 2010 with data from 2012 an overview will be provided of changes that have occurred in a 2 year span.

This chapter serves to answer part of the research questions from part 2 (well-being). The following questions will be addressed in this chapter:

- How do the personal characteristics and socio-economic situation of individuals receiving ART, and their households, change over time?
- How does ART impact HIV positive individuals, and their households, socio-economically?

6.2 General overview of data collected

6.2.1 Data collected on sample populations

In Chapter 3 an overview was provided on the sampling that took place in Roma N’gombe in 2010 and in 2012. In 2010 a total of 104 PLHIV on ART were interviewed and these people were asked to participate again in 2012. Out of these 104 people a total of 61 were re-interviewed in 2012 and a total of 57 were included in the dataset. Data of these 57 households is available for both 2010 and 2012 and will be discussed in this chapter.

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Total number of people</td>
<td>285</td>
<td>100.0%</td>
</tr>
<tr>
<td>Adults (18 and above):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>63</td>
<td>22.1%</td>
</tr>
<tr>
<td>Female</td>
<td>78</td>
<td>27.4%</td>
</tr>
<tr>
<td>Children (below 18):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>74</td>
<td>26.0%</td>
</tr>
<tr>
<td>Female</td>
<td>70</td>
<td>24.6%</td>
</tr>
</tbody>
</table>

Table 6.1: Number of male/female adult/children in 2010 and 2012

From the above we can see that the size of the group as a whole has stayed the same. There are some minor differences between the years. In 2010 there were almost as many adults as children while in 2012 there are more adults than children, this difference is not statistically significant. Changes in household composition can be due to household members joining or leaving the household (this can be because people have moved away or joined households but can also be due to deaths and births), but also household members who were considered to be children (<18 years) in 2010 may in 2012 be considered as adults.

74 There were a number of reasons why people were not re-interviewed, this is discussed thoroughly in Chapter three section 3.2.2 Survey Population, of which the main two reasons were that people had moved (35%) or people were untraceable (32%).

75 Reasons for exclusion include incomplete surveys as well as not meeting the criteria.
6.2.2 Comparing household characteristics 2010-2012
Both in 2010 and in 2012 details about the households and the household members were collected. These are discussed in this sub section.

Age
The median age for adults is listed below:

<table>
<thead>
<tr>
<th></th>
<th>Adults</th>
<th></th>
<th>Children</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2010</td>
<td>2012</td>
<td>2010</td>
<td>2012</td>
</tr>
<tr>
<td>25th percentile (Q1)</td>
<td>22</td>
<td>22</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Median</td>
<td>35</td>
<td>36</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>75th percentile (Q3)</td>
<td>45</td>
<td>47</td>
<td>14</td>
<td>14</td>
</tr>
<tr>
<td>Mean</td>
<td>35.3</td>
<td>36.5</td>
<td>9.4</td>
<td>9.8</td>
</tr>
</tbody>
</table>

Table 6.2: Mean age for adults and children in 2010 and 2012

From the above table we can see that the age for both children and adults has increased slightly between 2010 and 2012.

Sex
In 2010 the male to female ratio was 1:1.1 and in 2012 this was 1:1.2. As previously seen the age group 20-49 has been heavily impacted by the HIV epidemic. For this group the male to female ratio was 1:2.1 in 2010 and 1:2.2 in 2012.

Marital status
The marital status of adults in 2010 is largely the same in 2012. In 2010, 34.8% of the adults were single, 40.4% was married, and 15.6% was widowed. In 2012 there was a slight increase in the percentage of adults with a single (38.4%) or widowed (19.5%) status and slightly lower percentage of people who are married (37.7%).

Taking a closer look at the increase in the number of people who became widowed it can be seen that the majority of the people who became widowed are women. In 2010 the population surveyed included 22 people who were widowed, of this 2 were male and 20 were female. In 2012 there were 31 people who were widowed of which 3 were male and 28 were female. This may in part explain the increase in number of females per male in the study population.

As was seen previously the age group 25-49 is particularly affected by the HIV epidemic. The changes in marital status for adults between 2010 and 2012 are presented in figure 6.1.

![Martital status (age group 25-49)](image)

Figure 6.1: Changes in marital status of adults between 25 and 49 years between 2010 and 2012
When looking at the respondents (PLHIV on ART) and comparing their marital status from 2010 to 2012 we can see a similar pattern for the percentage of people who are married and widowed; with a decrease of the percentage of married people and an increase in the percentage of widowed people. Within this group the percentage of people who are single, in both 2010 and 2012 is around 5%.

Taking a closer look at the respondents we can see that 80.7% of all the respondents have the same marital status in 2012 as they had in 2010. From the 57 respondents 11 have a different marital status than they had in 2012, five have become widowed, three have separated/divorced, and three have married.

**Household situation of children**

Information was collected about with which biological parent(s), if any, children were living: in 2010 81.3% of all children were living with at least one of their biological parents, this was 89.6% in 2012.

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Both Parents</td>
<td>49</td>
<td>45</td>
</tr>
<tr>
<td>With Mother</td>
<td>61</td>
<td>64</td>
</tr>
<tr>
<td>With Father</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Neither Parents</td>
<td>27</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>144</td>
<td>125</td>
</tr>
</tbody>
</table>

*Table 6.3: Living situation of children in terms of with which biological parent(s) they are living with*

The number of children that lives with their mother has decreased from 110 to 109 while the number of children living with their father has decreased from 56 to 48. Already in 2010 we could see that more children were living with their mother than with their father and in 2012 we can see that this is even more the case.

Both in 2010 and in 2012 almost all children who lived with both their biological parents lived in households where one of their biological parents was the head of the household (100% in 2010 and 97.8% in 2012). In households where children lived with only their biological mother, the head of the household was their mother around two thirds of the time in both 2010 and 2012. The other one third was made up of households headed by the children’s step-father (11.5% in 2010 and 10.9% in 2012), headed by one of the children’s grandparents (18% in 2010 and 17.2% in 2012), and finally in 2012 an additional 7.8% of the households was headed by a nephew/niece. There were only a few households where the children lived with only their biological father, in 2010 all these children lived in households that were also headed by their biological father. In 2012 there were only three children who lived with only their biological father of these two children lived in a household where their father was also the head of the household and the other child lived in a household which was headed by a grandparent. Households where children do not live with any of their biological parents were headed by: the children’s grandparent(s) in 48.1% (in 2010) and 46.2% (in 2012), the children’s nephew/niece in 37.0% (in 2010) and 53.8% (in 2012), and finally in 2010 11.1% of these households were headed by the children’s older siblings.

From all children in 2010 38.2% of the children were single or double orphans. This was 54.4% in 2012. This difference was found to be statistically significant (p=0.008). Out of all the orphans the percentage of double orphans was 16.4% in 2010 and 14.7% in 2012, the percentage of maternal orphans was 10.9% in 2010 and 2.9% in 2012, and finally the percentage of paternal orphans in 2010 was 72.7% and 82.4% in 2012. In actual numbers, in 2012, there was one more child who is a double orphan, 4 less children who were maternal orphans, and 16 more children who were paternal orphans compared to 2010. Looking at the distribution of paternal

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76 Chi square p=0.055

77 Based on a Chi-square test
orphans amongst all children in 2010 and in 2012 it can be seen that in 2010 27.8% of all children were paternal orphans and this had increased to 44.8% by 2012 (p=0.00478).

Children and education
In Zambia education for children between the age of 7 and 14 is mandatory, and in theory should also be free of charge79. In 2010 from all children between the ages of 7 and 14 79.1% was attending school, this was higher in 2012 where for the same age group 87.9% was attending school80. For the age group 7-17 years the percentage of children attending school was the same in 2010 (79.0%) as in 2012 (78.7%).

Children and work
The majority of the children aged between 7 and 17 are reported to assist at home with household chores, around 90% in both 2010 and 2012. A small percentage in this age group is reported to be too young to do any work. In addition, a small number of children in this age group is working for pay or profit; the percentage of children working for pay/profit is slightly higher in 2010 (8.4%) than in 2012 (3.4%).

6.3 Research findings differences 2010 – 2012

6.3.1 Employment
In 2010 the devastating effects of HIV were seen on a number of areas, one of these was employment. It was shown that from all the respondents 94% reported that they were able to work before they became ill and that this percentage had dropped to 21% when people started with ART. Not only the ability to perform work, but also the type of work people were able to perform, was affected. Where almost 70% of the respondents, who were able to work, were working for some form of payment/profit before their illness this was only 8% at the start of ART. The work situation in 2010 had improved considerably from the start of ART where 96% of all the respondents reported to be doing some form of work and 48% of these were working for payment/profit.

Looking more closely at the respondents who were interviewed both in 2010 and in 2012 it can be seen that in 2010 52.6% of the respondents were working for payment/profit and this had increased to 63.2% in 201281. This is in line with what was seen in 2010 where “a rise in the number of people performing jobs for wages payment/profit can be seen the longer they have been receiving cART” (Reijer, 2010:28). In addition this is also in line with the conclusion suggested in 2010 that the longer people are on ART the more they recover.

Comparing work situations between 2010 and 2012 it can be seen that almost 70% of the people have not changed their employment status. When focussing on the specific work situation of individuals, rather than as a group, it was seen that from the 63.2% of the people who were working in 2012 65.7% were already working for payment/profit in 2010. A similar situation could be seen for people who were not working in 2012. From this group 71.4% was also not working in 2010.

78 Based on a Chi-square test.
79 Zambia’s education is supposed to be free for this age group and all children are expected to go to school, this is however often not the case. While officially school should be free for this age group this does not mean that there are no costs involved, for example: school uniforms, PTA contributions, books, etc.
80 Chi-square p=0.188
81 Chi-square p=0.255
In 2010 a comparison was made between the employment situation of people and the duration that they had been on medication. There was a rise in the number of people performing jobs for pay/profit the longer they had been receiving ART. To do this two groups were made, the first group contained people who had been on ART between 2-3 years and the second group contained people who had been ART for 4-6 years. By placing the same people in the same group that they were in in 2010 we can compare these two groups for the period 2010-2012. This provides the following results:

From the above it can be seen that for both the groups the percentage of people working for pay/profit has increased. Where 50% of the people who had been on ART for 2-3 years in 2010 were working for pay or profit this was just over 70% two years later in 2012. An increase was also seen for the group who had been on ART for 4-6 years in 2010 where just under 55% was working for pay or profit and in 2010 this had increased to 60% in 2012.
People who started ART 4-6 years ago in 2010 were amongst the first in Zambia to start with the treatment and as such often started at a very late stage during their illness. In 2010 it was seen that the later a person starts with treatment the more they have lost and the more they have to recover\textsuperscript{82}. As such, the recovery period and outcomes are expected to be lower for people who start treatment late compared to those who start treatment early. Recovery in the first couple of years at first goes rapid and while it does appear to continue, although less rapidly, for many years afterwards the starting position is expected to impact the eventual outcome\textsuperscript{83}.

### 6.3.2 Income

Household income is not solely dependent on whether or not the respondent is able to work and on what type of work he/she does. Respondents are not necessarily the main breadwinner of the households and some households may have multiple sources of income.

The main source of income for the household was discussed in both 2010 and 2012. The type of income that the household depends on can make huge differences in the income level and stability of the household income. Here a differentiation is made between paid work/piecework\textsuperscript{84}/own business/ other. Paid work is the most stable and often has the highest incomes. Piece work is probably the least stable and depending on the success someone has in finding work on a day to day basis can have varying income levels. Own business is less unstable than piece work, and can even be supplemented with piece work, but like piece work often has a fluctuating income. Both piece work and own business are often affected by various external factors, such as season and other people’s income (monthly fluctuations).

Comparing type of employment for the different years and also for the duration of ART can provide us with an insight into the changes over time. Similarly to what was done in the previous section here too households are placed in the same groups as they were placed into in 2010. This gives us the following:

<table>
<thead>
<tr>
<th>Source</th>
<th>Total (n=57)</th>
<th>Group 1 (ART years 2-3 in 2010) (n=18)</th>
<th>Group 2 (ART years 4-6 in 2010) (n=35)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid work</td>
<td>38.6%</td>
<td>53.7%</td>
<td>22.2%</td>
</tr>
<tr>
<td>Piece work</td>
<td>31.6%</td>
<td>9.3%</td>
<td>33.3%</td>
</tr>
<tr>
<td>Own business</td>
<td>19.3%</td>
<td>24.1%</td>
<td>27.8%</td>
</tr>
<tr>
<td>Other</td>
<td>10.5%</td>
<td>12.9%</td>
<td>16.7%</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Table 6.4: Source of household income for total group and for the two “duration on ART” groups formed in 2010 comparing 2010 and 2012

From the above we can see that the percentage of households who say that the main source of income comes from paid work has increased from 2010 to 2012 for the group as a whole and for the two sub groups. The increase of the number of people who have paid work in the “ART 2-3 years” has more than doubled and has even superseded the percentage that was found in 2010 in the group “ART 4-6 years”. While own business has

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\textsuperscript{82} When a household faces a situation in which one of its members faces illness a number of coping mechanisms may be put into place. As a result of illness and it’s impacts jobs may be lost, assets sold, family may be asked for assistance, etc. In Chapter two traditional coping mechanisms and strategies that are often put into place are discussed in more detail.

\textsuperscript{83} The physical well-being, at the time of the initiation of ART, might be another factor determining the well-being of people after a specific period of time. Low CD4 cell counts at the initiation of ART may have long term and profound impacts on the physical well-being on individuals. For more information regarding this please see “Text Box 7.1: CD4 cells and CD4 count – What it is and how it works” and “Text Box 7.2: ART and CD4 count” in Chapter 7 in Section “7.2 Starting with ART”

\textsuperscript{84} Piece work is a term widely used in Zambia. Piece work is part time work which people search for on a day to day basis and for which he or she is paid a fixed amount per job.
also increased slightly the percentage of households who are dependent on piece work for their main source of income has decreased. This decrease is particularly visible in the “ART 2-3 years” group. This is in accordance with the trend seen in 2010 where it was seen that the longer people had been on ART the more stable their main source of income appeared to become.

While the type of employment appears to be more secure, this does not necessarily mean that their incomes are also improving.

<table>
<thead>
<tr>
<th></th>
<th>Total (n=57)</th>
<th>Group 1 (ART years 2-3 in 2010) (n=18)</th>
<th>Group 2 (ART years 4-6 in 2010) (n=35)</th>
</tr>
</thead>
<tbody>
<tr>
<td>25th percentile (Q1)</td>
<td>150,000.00</td>
<td>300,000.00</td>
<td>135,000.00</td>
</tr>
<tr>
<td>Median (ZMK)</td>
<td>250,000.00</td>
<td>500,000.00</td>
<td>250,000.00</td>
</tr>
<tr>
<td>75th percentile (Q3)</td>
<td>350,000.00</td>
<td>700,000.00</td>
<td>275,000.00</td>
</tr>
<tr>
<td>Mean (ZMK)</td>
<td>290,480.80</td>
<td>534,792.50</td>
<td>227,187.50</td>
</tr>
<tr>
<td>Mean (Euro)86</td>
<td>€ 46.06</td>
<td>€ 78.00</td>
<td>€ 36.03</td>
</tr>
</tbody>
</table>

Table 6.5: Monthly household income for total group and for the two “duration on ART” groups formed in 2010 comparing 2010 and 2012

<table>
<thead>
<tr>
<th></th>
<th>Total (n=21)</th>
<th>Group 1 (ART years 2-3 in 2010) (n=4)</th>
<th>Group 2 (ART years 4-6 in 2010) (n=19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>25th percentile (Q1)</td>
<td>200,000.00</td>
<td>300,000.00</td>
<td>160,000.00</td>
</tr>
<tr>
<td>Median (ZMK)</td>
<td>300,000.00</td>
<td>500,000.00</td>
<td>225,000.00</td>
</tr>
<tr>
<td>75th percentile (Q3)</td>
<td>400,000.00</td>
<td>700,000.00</td>
<td>250,000.00</td>
</tr>
<tr>
<td>Mean (ZMK)</td>
<td>393,809.50</td>
<td>607,724.10</td>
<td>205,000.00</td>
</tr>
<tr>
<td>Mean (Euro)86</td>
<td>€ 62.45</td>
<td>€ 88.64</td>
<td>€ 32.51</td>
</tr>
</tbody>
</table>

Table 6.6: Monthly household income for households whose main source of income is paid work; for total group and for the two “duration on ART” groups formed in 2010 comparing 2010 and 2012

From the previous tables it can be seen that the average household income has increased from 2010 to 201287. Here too the income did not only increase for the group as a whole but also for the two sub-groups again in accordance with the trend that the longer people have been on ART the more the situation improves.

85 Exchange rate for 2010 was 1 Euro to 6306.18 Zambian Kwacha on April 30th 2010 and exchange rate for 2012 was 1 Euro to 6856.22 Zambian kwacha on April 30th 2012. (Source: <http://www.xe.com/currencycharts/?from=EUR&to=ZMK&view=5Y> [Online], last visited: 29-01-2012)

86 See previous footnote.

87 The inflation rate in Zambia at the end of 2010 was 7.9 percent and at the end of 2011 was 7.2 percent (IMF, 2013). Taking these inflation figures into account it can be seen that in the Table 6.5 all incomes have increased over the two years. In Table 6.6 this is true for the total group and Group 1 but not for Group 2 where, using the above inflation figures, the income of €76.45 would have needed to increase to €88.43 euro if the purchasing power was to remain the same for this group.
Taking a closer look at the household income for households whose main source of income comes from paid employment it can be seen that here too there is an increase. Particularly the households who in 2010 had been on ART for 2-3 years have dramatically increased (more than tripled) their household incomes by 2012, from an average of 32.51 euro per household per month to 93.35 euro per household per month.

The changes in income between 2010 and 2012 are most likely not the result of the situation in Lusaka having improved between 2010 and 2012. The majority of the people included in this research do not have a formal job and as such would not directly benefit for wage increases. Pay rises where seen for a few jobs, such as nurses, police officers, and teachers. However for many other jobs, for example for guards at a security firm, no pay rises occurred between 2010 and 2012. The majority of the working population in Zambia earns their income from the informal sector and for these sectors it is far harder to predict if any changes have occurred. The living costs in Lusaka have been slowly increasing for many years now. For the urban poor such increases are challenging. However, fluctuating food and commodity prices may be even more problematic for the poor.

### 6.3.3 Assets
Households who face a situation in which one of the household members becomes ill often face a number of challenges. In the beginning years of ART the coping mechanisms that households may have put in place to deal with the situation may have been very similar to the situation prior to ART. One of the coping mechanisms that households used to deploy was the selling of assets. Particularly in the early years of ART it is expected that many people would have had to resolve to coping strategies.

Respondents were asked, in both 2010 and 2012, whether the household owned a TV, radio, bed, or mobile phone and how many. For all assets, except for beds which remained at 77.2%, the percentage of households who said that they owned one of the above-mentioned assets increased.

![Percentage of households owning assets](image)

**Figure 6.4: Percentage of household reported to own specific asset, differences between 2010 and 2012**

88 “Take-home pay” (the salary of employees after the deduction of statutory taxes) for a security guard at a firm can be anywhere between 250,000 ZMK and 850,000 ZMK. This did not change between 2010 and 2012. (JCTR, 2010; 2011; 2012)

89 The Jesuit Centre for Theological Reflection (JCTR) have created a “basic needs basket” and have been reporting on this on a monthly basis for a number of urban locations since the 90’s. The Basic needs basket reports the prices for a number of basic food items, non-food items, and additional costs such as education and transport prices. The basic food basket also includes some comparative figures regarding wages. It does not reflect on the actual expenditures of urban families but on “ideal expenditures to promote proper nutrition and health for members of the average-sized Zambian family of six [since March 2012 these have changed to five]. The food and non-food items that form the basket have not been chosen arbitrarily, but represent basic, preferred goods that are commonly purchased by those urban families that can afford the costs and would ideally be purchased by all Zambian families” (JCTR, 2006:10). It is quite difficult to reflect and report on economic changes and wage changes that have occurred in Zambia between 2010 and 2012. However, the JCTR basic food baskets may provide an indication. In the “Appendix 2: Basic Needs Basket” the basic food basket for April 2010, March 2011, and April 2012 have been included.
The number of assets that were owned per household also increased for all assets, for example: there was a ratio of just over 0.8 phones per household in 2010 this is now just under 1.1 phones per household.

Looking at the duration of ART in 2010 it was seen that here too the longer people had been on ART the more households owned certain assets and the more of these assets they own. In 2010 households where the respondent had been on ART for 4-6 years owned more assets than households where the respondent had been on ART for 2-3 years. Using the same groups their situation in 2012 is compared to the situation in 2010. The general trend that can be seen is that the percentage of households who own assets has increased or has stayed the same between the years 2010 and 2012.

<table>
<thead>
<tr>
<th></th>
<th>Total (n=57)</th>
<th>Group 1 (ART years 2-3 in 2010) (n=18)</th>
<th>Group 2 (ART years 4-6 in 2010) (n=35)</th>
</tr>
</thead>
<tbody>
<tr>
<td>TV</td>
<td>43.9%</td>
<td>49.1%</td>
<td>38.9%</td>
</tr>
<tr>
<td>Radio</td>
<td>35.1%</td>
<td>42.1%</td>
<td>27.8%</td>
</tr>
<tr>
<td>Phone</td>
<td>61.4%</td>
<td>77.2%</td>
<td>61.1%</td>
</tr>
<tr>
<td>Bed</td>
<td>77.2%</td>
<td>77.2%</td>
<td>77.8%</td>
</tr>
</tbody>
</table>

Table 6.7: Percentage of households who own a specific asset - changes between 2010 and 2012 for total group and two duration of ART groups.

The general trend that can be seen in the graph above is that the percentage of households who own assets has increased or has stayed the same between the years 2010 and 2012. In the second group a decrease in the percentage of households who own a TV between 2010 and 2012 can be seen.

6.4 Conclusion

This chapter focused on a group of PLHIV on ART in Roma N’gombe who were interviewed in 2010 and again in 2012. Data from 2010 was compared with data from 2012 and trends that were found in 2010 were re-explored. This chapter served to answer the following questions:

- How do the personal characteristics and socio-economic situation of individuals receiving ART, and their households, change over time?
- How does ART impact HIV positive individuals, and their households, socio-economically?

In the first section a number of personal characteristics of the households were discussed and data from 2010 and 2012 were compared. Following this some of the main research findings from 2010 were re-explored.

General Findings

In 2010 a total of 104 households were included in the survey, in 2012 61 of these were re-interviewed and from these 57 were included in the dataset. Four were excluded because of incompleteness of surveys as well as not meeting the criteria. The 57 households in 2010 comprised of a total population of 285 people, the same households in 2012 had a total population of 284. In 2010 there were 144 children in these 57 households and in 2012 there were 125 children in the same households.

The male to female ratio for the study population was 1:1.1 in 2010 and 1:1.2 in 2012. The age group 20-49 years carries the heaviest burden of the HIV epidemic and here the male to female ratio was 1:2.1 in 2010 and 1:2.2 in
Already in 2010 there were clearly more women than men in the most productive age group and in 2012
the percentage of men further declined.

The marital status of the adult population has largely stayed the same over the two years. A slight increase in the
percentage of people who were widowed was visible. The majority of the widows was female, this was the case in
2010 and in 2012. Moreover from the nine people who were widowed between 2010 and 2012 eight were female.
Within the age group 25-49 years a higher proportion of widows was present, compared to the adult population as
a whole, and also when comparing 2010 and 2012.

The percentage of children living with one or both their biological parents increased slightly between 2010 and
2012. However, the total number of children living with one or both parents actually decreased. In both years
there were more children living with their biological mother than with their biological father. In 2010 110 children
were living with their mother and 56 with their father, in 2012 109 were living with their mother and 48 with their
father. The majority of the children who live with their father also live with their mother, the reverse is not true.

In 2010 38.2% of all children were single or double orphans; this was 54.4% in 2012. Out of all the orphans the
majority were paternal orphans (72.7% in 2010 and 82.4% in 2012), followed by double orphans (16.4% in 2010
and 14.7% in 2012), and finally maternal orphans (10.9% in 2010 and 2.9% in 2012).

In 2010 a rise in people (PLHIV on ART) working for payment/profit was seen the longer people were on ART.
The percentage of respondents (PLHIV on ART) who reported that they were working for payment/profit
increased further from 52.6% in 2010 to 63.2% in 2012. The groups of PLHIV on ART were looked at in 2010,
namely those on ART for 2-3 years and those on ART for 4-6 years. Using the same groups, changes between
2010 and 2012 were explored and it was seen that for both groups the percentage of people who were working
for payment/profit had increased.

The main source of income as well as the household income was also discussed. For the group as a whole an
increase in the percentage of households who were dependent on paid work as their main source of income
could be seen (from 38.6% in 2010 to 53.7% in 2012). The percentage of households dependant on piecework,
which can be seen as one of the most insecure forms of household income sources, strongly decreased (31.6%
in 2010 to 9.3% in 2012). Using the same two groups (duration ART) as above a similar pattern could be seen.
The household income has also increased between 2010 and 2012. This increase was found for the group as a
whole and also for the two groups (duration ART). The income for households whose main source of income is
paid work has also increased and remains higher than the average household income for the group as a whole.
The percentage of households who own specific assets also increased between 2010 and 2012.

Discussion
Changes between 2010 and 2012 show an increase in the previously discussed feminisation of the HIV epidemic.
The increase in widows and orphans in the study group is largely due to the fact that men, rather than women,
continue to die. It is women who are losing their partners and children who continue to be orphaned paternally.
Increasingly children are no longer living with their biological father and those who are, almost always, also live
with their biological mother.

Socio-economically there appears to be an improvement. The main source of income of households has become
more secure: the percentage of households who now rely on paid work or have their own business has increased
and the percentage of people who rely on piece work has decreased. The average household income has
increased. A conclusion in 2010 was that people and their households need time to recover. The longer people
had been on ART the more they, and their households, appeared to recover. The results, presented in this
chapter, support this conclusion. In addition, this trend continues for a long time after the initial start of ART. In this chapter it was shown that even after 6-7 years of ART improvements are still visible.

It remains to be seen what the impact of the above mentioned feminisation may be on households. Additionally, it raises the question where this feminisation may be coming from. While a slight increase in the number of women per men was found the socio-economic situation has continued to improve. This may be seen as an indication that the loss of men, while it may have a negative influence, has not stopped the process of recovery.

ART is clearly mitigating some of the effects of the HIV epidemic. At the same time though, it is changing the face of society. ART is helping mothers to stay alive and be able to care for their children; however, women continue to lose their husbands and children their fathers. This has a direct impact on households and families. At the same time it will impact communities, and on the long run it affects all layers of society.
Chapter 7 – The influence of temporal contexts on well-being

7.1 Introduction

An overview of the collected data was provided for both the group as a whole and for the geographical locations separately in Chapter 5. This provided us with an impression of some of the personal characteristics of the individuals on ART and their households, an indication of their socio-economic situation, and an insight into the physical and mental health of the respondents. Following this, Chapter 5 provided information about a number of people who were interviewed in both 2010 and in 2012 and the data was compared. In Chapter 6 it could be seen that the trends that were found in 2010, and presented in Chapter 4, appear to have continued. While Chapter 6 provided an insight into how the situation may change over time, and showed that certain trends that were seen in 2010 indeed did continue into 2012, it will be interesting to look at the factor time in more detail.

In this chapter the “time” factor will be more closely looked at. People all started with ART at a different point; in different years and with varying degrees of HIV infection. All had differing socio-economic situations both before and during the start of ART, therefore it is not surprising that people also have a different socio-economic situation at the time of the fieldwork. These differences can be seen on a variety of fronts. For example in terms of physical health, material or even income levels, and even in terms of mental health. It is expected that people who start with ART in an early stage of HIV infection (when people are, for example, not yet suffering from frequent periods of illness and are still working) may recover quicker than people who start in a later stage of the infection (when people are, for example, bedridden and unable to work). The longer people take ART, the less these differences might become, but those who start in the early stages of the infection will recover quicker and more fully than those who start in a much more advanced stage of HIV infection (See “Text Box 7.1: CD4 cells and CD4 count – what it is and how it works” and “Text Box 7.2: ART and CD4 count”). However, there are individual differences and it is very well possible that someone who was bedridden, had lost 25% of its weight, and had a CD4 count below 50 cells per cubic microliter picks up quickly and has a good physical health after e.g. 12 months of ART. At the same time, a person who starts ART when most parameters are still favourable might not respond so well, e.g. due to side-effects of the therapy.

In this chapter the following questions will be answered:

- What were the personal characteristics and socio-economic status of individuals receiving ART before and at the start of ART?
- How do the personal characteristics and socio-economic status of individuals, and their household, before and at the start of ART determine the current well-being of individuals, and their households, receiving ART?
- How does ART affect the well-being of HIV positive individuals, and their households, who are receiving ART?

As explained in Chapter 3 people were asked questions regarding their and their households’ lives and situation at the time before the respondent was ill or experienced any periods of frequent illness, at the time that the respondent first started ART, and currently.

The current situation of households was discussed in Chapter 5. This chapter will focus on some of the characteristics that PLHIV on ART had in previous periods and how this may have influenced their current well-being. In Chapter 8 a more in depth view will be provided about the histories of the households and the stories of the respondents.
7.2 Starting with ART

ART became available in Zambia in 2004 and the provision of ART was rapidly up-scaled after this. Respondents in this study started ART in different periods and respondents came from two areas in Lusaka.

From the above we can see that some of the respondents have been receiving ART for almost a decade while others have been on ART for just over a year. The Ministry of Health in Zambia provides guidelines of when people should start with ART, this however does not mean that everyone starts with the same health level. Respondents were asked a number of questions regarding their health when they first started with ART.

From the 151 people on ART in the research project, 130 respondents (86.1%) were able to recall his/her CD4 count at the start of treatment. An overview of the distribution of the different CD4 counts:

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Kalingalinga</th>
<th>Roma N’gcombe</th>
</tr>
</thead>
<tbody>
<tr>
<td>25th percentile</td>
<td>100</td>
<td>145</td>
<td>89</td>
</tr>
<tr>
<td>Median</td>
<td>176</td>
<td>200</td>
<td>123</td>
</tr>
<tr>
<td>75th percentile</td>
<td>231</td>
<td>260</td>
<td>180</td>
</tr>
<tr>
<td>Mean</td>
<td>203.1</td>
<td>234.0</td>
<td>140.5</td>
</tr>
</tbody>
</table>

CD4 counts in Roma N’gcombe were, on average, lower than those in Kalingalinga. This means that people in Roma N’gcombe had a more advanced stage of HIV infection than people in Kalingalinga. Previously it was noted that the respondents from Roma N’gcombe also had earlier starting years than respondents from Kalingalinga. When ART was first introduced the used guidelines also had lower CD4 count thresholds for starting with ART, making it unlikely for people to start ART while still in a (reasonable) good physical condition and higher CD4 counts. During the first years, ART was available from a few clinics only, while at the same time large numbers of PLHIV in advanced stages were seen. Consequently, the majority of the people who started ART, in the first years, were those in advanced stages. In addition, few PLHIV without clear signs and symptoms of HIV infection were aware of their HIV status. Only when the people noticed the positive effect of ART, people looked for testing.
Text Box 7.1: CD4 cells and CD4 count – What it is and how it works

CD4 cells can be described as the managers of the immune system. CD4 cells are in fact several different cells, like in the management of an organisation. The variety of the cells enables the immune system to react to all kind of threats.

The number of CD4 cells per cubic microliter varies from 500-600 to 1,000-1,200 in a healthy person. The number of CD4 cells per cubic microliter varies during the day and variations of up to 40% within 24 hours are possible.

The graph shows the average pattern of HIV infection leading finally to AIDS and ultimately to death. On average this process takes 9 to 11 years. However, it is possible to live with untreated HIV infection for many more years while some people develop AIDS within 2 to 3 years. This is genetically determined.


Shortly after infection with HIV, the virus enters CD4 cells and starts multiplying. The immune system of the human body reacts to this by manufacturing antibodies. However, this takes some time, time in which the virus can multiply rapidly and destroy many CD4 cells. The highest concentration of HIV particles is found 3 to 6 weeks after infection. The concentration is reduced once the body starts making antibodies. At the peak of the virus concentration a dip in the CD4 concentration is seen, but this is restored to almost normal levels within 10 to 12 weeks after infection. Once HIV antibodies are formed, the HIV antibody test becomes positive. Normally this test becomes positive after 6 weeks, but it can take up to 12 weeks. With special laboratory technics over 99% of infections can be detected within 2 weeks, but these tests are expensive and not widely available. The newly infected person might have some flew-like symptoms in the first weeks after infection, but it might go completely unnoticed.

From this point in time onwards, a continuing battle takes place between the HIV and the human body. Every day millions of CD4 cells are infected and lost, while at the same time the body produces millions of new CD4 cells. However, there are more CD4 cells destroyed than added and slowly the total amount of CD4 cells drops and the number per microliter decreases. By the drop of the concentration of CD4 cells, the immune system is weakened and the person becomes more and more susceptible to all kind of infections. The first non-specific signs and symptoms of HIV infection occur when the CD4 count drops to below 400-500. Life threatening infections, caused by micro-organisms that normally do not cause infections, appear when the CD4 count drops to levels below 300-250 (opportunistic infections). At this stage the concentration of virus particles in the blood starts steadily to increase and an increasing number of CD4 cells are infected, until hardly any can be found and the person dies.
The group was split into two on the basis of CD4 count at the initiation of ART treatment, creating a group (n=72) with a CD4 count between 0-199 and one group (n=58) with a CD4 count of 200 and above. Comparing these two groups, to the areas that the respondents were from, shows that just under 77% of the respondents from Roma N’gombe fall in the group with the lower CD4 count while this was just under 45% in Kalingalanga. It should be noted that Roma N’gombe was one of the first areas where ART became available in Lusaka, and as mentioned previously, during this time the majority of the people who started with ART were in advanced stages of HIV infection.

Text Box 7.2: ART and CD4 count

Antiretroviral Therapy (ART) aims at blocking the replication of HIV and prevents as a consequence the further destruction of CD4 cells. After a few weeks of ART the concentration of HIV drops and slowly the CD4 count increases. However, the later in the disease progression ART starts, the less likely it is that a full recovery is made. As can be seen from the following graph, it is less likely that CD4 levels of 500 and higher are reached after some years of ART when the starting CD4 count is below 200. It is more likely that these persons have not fully regained their physical health in comparison to people whose initial CD4 count was 500 or higher.

![Graph showing CD4 count over years](http://example.com/graph.png)

Source: Sax (2011)

The latest recommendations for the start of ART in the USA* for adolescents and adults is to offer ART to any HIV infected person, regardless clinical condition, CD4 count, or any other parameter, in order to stop disease progression.

Not only the numbers of CD4 cells are not fully restored, it might also be that one or more the various groups of CD4 cells are not recovered at all (or only partly). The diversity of the CD4 cells is therefore reduced and the quality of the immune system also. In conclusion, it can be said that it is unlikely that people who start ART with a low CD4 count, i.e. below 200 cells per cubic microliter, will recover fully physically.


The group was split into two on the basis of CD4 count at the initiation of ART treatment, creating a group (n=72) with a CD4 count between 0-199 and one group (n=58) with a CD4 count of 200 and above. Comparing these two groups, to the areas that the respondents were from, shows that just under 77% of the respondents from Roma N’gombe fall in the group with the lower CD4 count while this was just under 45% in Kalingalanga. It should be noted that Roma N’gombe was one of the first areas where ART became available in Lusaka, and as mentioned previously, during this time the majority of the people who started with ART were in advanced stages of HIV infection.

---

90 This was tested using a Chi2 test, p=0.001.
Just over 37% of all respondents indicated that they were bedridden at the time they started ART. This indicates that their physical health was very poor (end stage of the HIV infection). Comparing CD4 count to whether or not the respondent was bedridden at the start of ART provides us with the following:

![Figure 7.2: CD4 count in relation to whether or not respondent was bedridden at start of ART](image)

From the above we can see that people with a lower CD4 count are also more likely to have been bedridden, this was found to be statistically significant\(^91\).

Respondents were also asked if they needed assistance\(^92\) when they first started with ART. From the 151 respondents 107 (70.9%) reported that they needed assistance. People with a lower CD4 count were more likely to have needed assistance than people with a higher CD4 count; 76% of the respondents in the lower CD4 count group needed assistance compared to 58.6% in the higher CD4 count group\(^93\). Similar results can be seen for respondents’ ability to work at the start of ART where in total 51.7% reported they could work but when taking CD4 count into consideration we can see that people with a higher CD4 count are more likely to be able to work than people with a lower CD4 count. Just over two thirds of the respondents who reported that they were unable to work at the start of ART had a CD4 count bellow 200. People with a higher CD4 count are more likely to be able to work than people with a lower CD4 count. This result was found to be statistically significant\(^94\).

The health outcomes of individuals have been connected to their CD4 count at initiation of ART. An insight into the consequences of low CD4 counts at initiation of ART has also been provided above. It was seen that people with a lower CD4 count were more likely to be bedridden, unable to work, and in greater need of assistance than people with a higher CD4 count. When people start with ART and what their physical condition is at the initiation of ART is likely to impact the outcomes of their current situation.

### 7.3 Time and Trajectories

#### 7.3.1 Socio-economic outcomes

In this section a number of socio-economic indicators will be looked at and compared to the different time periods that PLHIV on ART have gone through. Where possible these will also be compared to the CD4 count that respondents had at the start of ART as well as by geographic area.

\(^{91}\) This was tested using a Chi2 test, \(p=0.006\).

\(^{92}\) The type of assistance people needed included: personal care (such as bathing and dressing), assistance with household chores (such as cooking, washing clothes, fetching water, and cleaning), financial support (such as transport money to go to the clinic, for medical tests, and school fees for children), and food assistance.

\(^{93}\) This was tested using a Chi2 test, \(p=0.030\).

\(^{94}\) This was tested using a Chi2 test, \(p=0.011\).
**Employment**

Comparing employment situations of respondents on ART from before illness to their current situation can provide us an insight into their recovery process. Additionally we will also look at the employment status of respondents at the time they first started with ART. This allows us not only to compare the before to after situation but additionally what changed in their employment situation during their illness.

Currently out of the 151 respondents 27 (17.9%) reported not to be doing any work. This is virtually the same situation as before people were ill/started with ART (17.2%). At the start of ART 75 (49.7%) of the 151 respondents reported not to be working. A recent study in South Africa finds a similar pattern and additionally shows that the time to recovery of employment to normal levels can take up to 4 years after ART initiation (See Bärninghausen et al., 2012).

Returning to work, or at least performing some form of work, however says little about the type of work people are engaging in. Just under 10% of the respondents, both before ART and currently, who were able to do some form of work reported that they were not working for payment or profit but were doing household chores. This was more than double (23.2%) at the initiation of ART.

At the start of ART only 41 of the 151 respondents were still working for payment/profit. Currently, 110 respondents are engaged in work involving some form of payment/profit. Before illness this was 102, however it should be noted that before illness 8 respondents were, instead of working, attending some education facility compared to none currently.

On first appearance it may seem that the situation, in terms of employment, is currently comparable to that before illness\(^5\). However, when looking at the type of employment people are engaged in a difference can be seen. Before illness more people were employed in formal and informal employment compared to the current situation. Formal employment can be seen as the most income secure type of employment; this is followed by informal employment. When people are unable to secure either formal or informal paid jobs they can either start their own business, and when this is not possible (due to for example financial constraints) the following, and least income secure, option is piecework.

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\(^5\) In the graph it can be seen that 49 respondents were not working prior to their illness while 41 are currently not working. It should be noted that 8 of the 49 respondents who were not working for payment/profit prior to their illness were attending a educational facility. During the other two periods none of the respondents were attending an educational facility.
The previous figure provides an overview of how the group as a whole has changed over time in terms of type of work for payment/profit they were doing. Comparing the employment situations of individuals over time can give us a better understanding of the trajectories people go through. As such, for each individual his/her employment status was looked at in three points in time and differences and similarities were recorded. Comparing the group as a whole, as was done above, does not give us the whole story. It was seen that the percentage of people working may currently be comparable to what it was prior to their illness, however it was also seen that the type of work people are doing is not the same as prior to their illness. Additionally it tells us little about who is who and whether people who were prior to their illness, for example, formally employed are currently the same people who are formally employed. In the flowchart below the employment situation of all respondents is followed from before illness to the start of ART till the current working situation

From the above figure it can be seen that there are various trajectories that people can go through. From the 102 respondents that were working before illness 34 were still able to work at the start of ART and 33 of these are currently still working. The 68 respondents, of the 102 who were working before the start of their illness, stopped working at the start of ART and of these 45 are currently working. This suggests that not everyone recovers and for those who are able to continue working during their illness there is a higher chance they are currently still working. Not stopping with work at the start of ART not only suggests that these respondents were physically still able to work it also means that they won’t need to recover what others have lost.

The flowchart depicted in figure 7.4 provides an overview of how respondent’s trajectories can go in terms of working for payment/profit or not working for payment/profit. While it does provide some outcomes of types of employment people are currently engaged in this still does not show if people who were engaged in formal employment prior to their illness have returned to this, or similar type of employment.

96 The category “other” in flowchart 7.X includes: landlord (n=4), volunteer (n=4), sex worker (n=1), and retired (n=1).
While there are too many trajectories possible to show here it is fruitful to give an example of one. In the next flowchart the employment trajectories of people who were formally employed prior to their illness is shown.

**Figure 7.5: Employment trajectory of respondents who were formally employed prior to their illness.**

From the above figure it can be seen that from the 151 respondents 102 were working for payment/profit prior to their illness. From these 102 respondents a total of 26 were formally employed prior to their illness. When these 26 respondents started with ART only four were still formally employed and the other 22 were not working for payment/profit. Currently the same four people who were formally employed prior and at the start of ART are currently still formally employed. A total of 10 respondents of the 22 respondents who were not working for payment profit at the start of ART but were formally employed prior to their illness are currently again formally employed. The other 12 respondents who were not working for payment/profit at the start of ART but were previously formally employed are currently not formally employed: 6 are not working and 6 are doing other work for payment/profit.

All of the respondents who were formally employed prior to their illness and were able to continue doing so at the start of ART are currently all still formally employed. Those who were no longer formally employed at the start of ART are less fortunate and only 10 were able to return to formal employment. Respondents who had to stop working when they started with ART will first have needed to regain their strength and recover physically. Following this they may have been able to return to work, the above however would suggest that they were not all able to return to their previous job or find new formal employment.

In Chapter 5 it could be seen that people living in Roma N'gombe had a lower socio-economic level in 2012 than people in Kalingalinga. Employment opportunities and socio-economic status is likely to have an impact on the
recovery of PLHIV on ART. Looking at the current employment status of PLHIV on ART from these areas provides us with the following:

![Employment status of PLHIV on ART: current](image)

**Figure 7.6: Current employment status of respondents by location**

49% of the respondents in Roma N'gombe are currently not working for any payment/profit compared to 14% in Kalingalinga. Moreover, respondents in Kalingalinga are more frequently involved in formal (19%) and informal (33%) employment compared to Roma N'gombe (respectively 4% and 9%). This result is relatively unsurprising seeing the results that were found in Chapter 5. However, comparing the employment status of PLHIV on ART over time may provide a better insight into how location may influence employment outcomes.

Prior to illness respondents from Kalingalinga were more often formally and informally employed than respondents from Roma N'gombe. 37% of the people in Roma N'gombe were not working, which is lower than the current situation. However, it should also be noted that in Kalingalinga there were more people not working (30%) than is currently the case. Slightly more respondents in Roma N'gombe currently have their own business or are involved in piecework than before their illness. The number of respondents involved in formal and informal employment in Kalingalinga has almost stayed the same, and only a visible increase can be seen in the number of respondents who have their own business. In Roma N'gombe we instead see a stark decrease in the number of people who are employed formally or informally: before illness 12% of the respondents was formally employed and 23% was informally employed, currently this is respectively 4% and 9%.

At the start of ART, 81% of the respondents in Roma N'gombe and 68% of the respondents in Kalingalinga was not working at all. A total of 20% of the respondents in Kalingalinga was still either formally or informally employed, compared to 2% in Roma N'gombe. Getting a job in Zambia is a challenge for many people as there are not enough jobs, as such losing your job can have long term effects. Even when people recover and are physically able to return to work there is no guarantee that they will be able to find work. Whether or not someone finds work after recovering from illness may also be dependent on their location. As such it is important to look at individual changes over time and per location.

More than 20% of the respondents in Roma N'gombe were both not working for payment/profit before illness and currently, compared to just over 5% in Kalingalinga. Instead 46% of the people in Kalingalinga is currently doing the same or similar work to what they were doing before their illness, this is 26% in Roma N'gombe. More respondents in Kalingalinga (24%) went from not working for payment/profit, before their illness, to currently working for payment/profit than in Roma N'gombe (16%). And three times more people in Roma N'gombe went from working for payment/profit before illness to currently not working for payment/profit than in Kalingalinga.
Between “before illness” and the “current situation” people would have, at the start of ART, been at their worst physical condition. While the situation is currently better than it was at the start of ART it has not reached the level that it was at before, particularly not in Roma N’gombe. Taking a closer look at the situation of people at the start of ART, and comparing this to the other two periods, we can get a better understanding into the trends mentioned above.

Comparing the employment changes over time and between the two geographic areas provides us with a number of observations. The percentage of people who were working for payment and profit before illness and were able to continue doing so at the start of ART is higher in Kalingalinga (28%) than in Roma N’gombe (14%). Additionally, the number of people who reported that they had been working for payment/profit before illness but were no longer doing so at the initiation of ART was higher in Roma N’gombe (49%) than in Kalingalinga (43%). Once PLHIV have started with ART their physical health starts to improve and often they then try to go back to doing work for payment/profit. This is reflected in the high number of people who were not working at the start of ART but are currently working. In Kalingalinga 55% of the people who were not working at the start of ART are currently working, compared to 35% in Roma N’gombe.

There are more people who initially are not working for payment/profit in Roma N’gombe than in Kalingalinga. Less people are able to remain employed in Roma N’gombe than in Kalingalinga. Additionally, more people also stopped working at the start of ART in Roma N’gombe than in Kalingalinga. Finally, less people in Roma N’gombe returned to work for payment/profit after they started ART than in Kalingalinga. As such, people in Roma N’gombe not only have a worse starting position, they also appear to be able to recover less than people in Kalingalinga.

In the previous section CD4 counts of respondents were discussed. It was seen that people with lower CD4 counts at the start of ART were more likely to have been in a worse physical health condition than people with a higher CD4 count. This is likely also to have impacted their possibilities for working for payment/profit, and may still be impacting them.

When comparing the working situation of people before their illness to their current situation it can be seen that there is a higher percentage of people who had a higher CD4 count when they started with ART who were working for payment profit both before their illness and after their illness. 46% of the people who had a CD4 count below 200 were working both before and currently for payment/profit, compared to 66% of the people with a CD4 count of 200 and above. People with a lower CD4 count at the start of ART were more often not working for payment/profit at the start of ART, than people with a CD4 count of 200 and above. Similarly people with a CD4 count of 200 and above who were working prior to their illness were more often still working at the start of ART than people with a CD4 count of below 200. Both groups have a large percentage of people who were working for payment/profit prior to their illness but were not doing so anymore at the start of ART. This was 47% for people with a CD4 count below 200 and 40% for people with a CD4 count of 200 and above.

Comparing the situation after the start of ART to the current situation shows a similar pattern as above. The main difference is in the reversal of large numbers of people going from working for payment/profit to not working for payment or profit who are instead now going from not working for payment/profit to working for payment/profit: people are regaining their ability to work and are, where possible, returning to work. This can be seen in the figure 7.7.

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97 This was tested using a Chi2 test, p=0.025.
Figure 7.7: Changes in working for payment/profit or not working for payment/profit of respondents between starting with ART and currently by CD4 count level

Income

In terms of income it was seen in Chapter 5 that the mean income of households was lower in Roma N’gombe than in Kalingalinga. Above it was noted that a low CD4 count at the start of ART can impact employment situations and that this can have long lasting effects. Household income may shift considerably if an income source is lost, not only initially when, for example, a job is lost, but also on the long term. Additionally, it was seen that many people stopped working when they became ill, and that while many have now returned to work this does not mean that they have returned to the work that they were doing prior to their illness.

Of the 151 respondents a total of 130 were able to report their CD4 count at the start of ART. The average household income was available for 147 respondents; of these 147 a total of 126 knew their CD4 count at the start of ART. From these 126 respondents, where the CD4 count and the average household income were available, 69 respondents had a CD4 count of below 200 and 57 had a CD4 count of 200 and above. Looking at the current household income in relation to the CD4 count at the start of ART the following can be seen:

<table>
<thead>
<tr>
<th>CD4 count: 0-199 (n=69)</th>
<th>CD4 count: 200+ (n=57)</th>
</tr>
</thead>
<tbody>
<tr>
<td>25th percentile (Q1)</td>
<td>ZMK 300,000.00 (~€46)</td>
</tr>
<tr>
<td>Median</td>
<td>ZMK 500,000.00 (~€77)</td>
</tr>
<tr>
<td>75th percentile (Q3)</td>
<td>ZMK 800,000.00 (~€123)</td>
</tr>
<tr>
<td>Mean</td>
<td>ZMK 615,768.10 (~€95)</td>
</tr>
</tbody>
</table>

Table 7.2: Mean monthly household income of respondents by CD4 count

From the table above it can be seen that the mean incomes of household where the respondent started with ART with a CD4 count of 200 and above is higher than for households where the CD4 count was below 200.

In Chapter 5 it was seen that the average income in Kalingalinga is higher than in Roma N’gombe. In this chapter it was seen that people in Roma N’gombe on average had a low CD4 count when starting with ART than people in Kalingalinga. As such, it is important to look at the effects of CD4 count on income levels in the two geographic areas separately.

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* Exchange rate 1 euro = 6,500.00 Zambian Kwacha
From the 130 respondents who remembered their CD4 count, 87 lived in Kalingalinga and 43 in Roma N’gombe. In total, the average household income was available for 147 respondents; 94 in Kalingalinga and 53 in Roma N’gombe. In Kalingalinga, there were 87 respondents where both the CD4 count and the average household income was available, this was the case for 39 respondents in Roma N’gombe. In Kalingalinga, out of the 87 respondents, 39 had a CD4 count of below 200 and 48 with a CD4 count of 200 and above. In Roma N’gombe out of the 39 respondents, 30 had a CD4 count of below 200 and 9 had a CD4 count of 200 above. It should be noted that the group of respondents in Roma N’gombe who had a CD4 count of 200 and above is quite small.

### Table 7.3: Mean monthly household income of respondents by CD4 count in Kalingalinga

<table>
<thead>
<tr>
<th></th>
<th>CD4 count: 0-199 (n=39)</th>
<th>CD4 count: 200+ (n=48)</th>
</tr>
</thead>
<tbody>
<tr>
<td>25th percentile (Q1)</td>
<td>ZMK 400,000.00 (~€62)</td>
<td>ZMK 480,000.00 (~€74)</td>
</tr>
<tr>
<td>Median</td>
<td>ZMK 639,000.00 (~€98)</td>
<td>ZMK 725,000.00 (~€112)</td>
</tr>
<tr>
<td>75th percentile (Q3)</td>
<td>ZMK 900,000.00 (~€138)</td>
<td>ZMK 930,000.00 (~€143)</td>
</tr>
<tr>
<td>Mean</td>
<td>ZMK 701,641.00 (~€108)</td>
<td>ZMK 795,833.30 (~€122)</td>
</tr>
</tbody>
</table>

### Table 7.4: Mean monthly household income of respondents by CD4 count in Roma N’gombe

<table>
<thead>
<tr>
<th></th>
<th>CD4 count: 0-199 (n=30)</th>
<th>CD4 count: 200+ (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>25th percentile (Q1)</td>
<td>ZMK 300,000.00 (~€46)</td>
<td>ZMK 300,000.00 (~€46)</td>
</tr>
<tr>
<td>Median</td>
<td>ZMK 450,000.00 (~€69)</td>
<td>ZMK 500,000.00 (~€77)</td>
</tr>
<tr>
<td>75th percentile (Q3)</td>
<td>ZMK 650,000.00 (~€100)</td>
<td>ZMK 600,000.00 (~€92)</td>
</tr>
<tr>
<td>Mean</td>
<td>ZMK 504,133.30 (~€78)</td>
<td>ZMK 555,555.60 (~€85)</td>
</tr>
</tbody>
</table>

From the above, we can see that if we compare the average income in the two CD4 count groups in the separate geographical areas, that here too the average household income is higher in households where the respondent started with ART with a CD4 of 200 and above.

### Assets

Prior to the introduction of ART, many households resorted to selling off assets during periods of illness and death of household members as a coping mechanism. Many respondents were unable to work when they started with ART. During periods where household members are unable to work, particularly if this household member was previously working for payment/profit, this leads to income loss. Income loss may cause selling of assets. Households can own a variety of assets, and this can give us some indication of the socio-economic situation of households.

The percentage of households who owns a specific asset was looked at in relation to the CD4 count of respondents at the start of ART. Both for the group as a whole but also specifically for Kalingalinga, this is discussed. In addition to the percentage of households which reported to own a certain asset, the average number of assets that is owned per household was also looked at.

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99 Exchange rate 1 euro = 6,500.00 Zambian Kwacha
100 Exchange rate 1 euro = 6,500.00 Zambian Kwacha
### Table 7.5: Assets owned by household by CD4 count of respondent at start ART

<table>
<thead>
<tr>
<th>Asset</th>
<th>Percentage of households which own asset</th>
<th>Average number of asset per household</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CD4 count: 0-199 (n=72)</td>
<td>CD4 count_200+ (n=58)</td>
</tr>
<tr>
<td>TV</td>
<td>60%</td>
<td>74%</td>
</tr>
<tr>
<td>Radio</td>
<td>51%</td>
<td>69%</td>
</tr>
<tr>
<td>Mobile Phone</td>
<td>85%</td>
<td>91%</td>
</tr>
<tr>
<td>Matrass</td>
<td>86%</td>
<td>91%</td>
</tr>
<tr>
<td>Bed Frame</td>
<td>83%</td>
<td>91%</td>
</tr>
<tr>
<td>Blanket</td>
<td>90%</td>
<td>98%</td>
</tr>
<tr>
<td>Storage Cupboard</td>
<td>35%</td>
<td>45%</td>
</tr>
<tr>
<td>Display Cupboard</td>
<td>29%</td>
<td>40%</td>
</tr>
<tr>
<td>Sofa Chairs</td>
<td>40%</td>
<td>45%</td>
</tr>
<tr>
<td>Morris Chairs</td>
<td>38%</td>
<td>34%</td>
</tr>
<tr>
<td>Bicycle</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td>Kitchen chair</td>
<td>14%</td>
<td>14%</td>
</tr>
<tr>
<td>Table</td>
<td>58%</td>
<td>72%</td>
</tr>
<tr>
<td>Working car</td>
<td>1%</td>
<td>12%</td>
</tr>
<tr>
<td>Not working car</td>
<td>4%</td>
<td>3%</td>
</tr>
</tbody>
</table>

In the previous graph it can be seen that in 11 out of the 15 assets a higher percentage of households wherein respondents started with ART with a CD4 count of 200 and above owned specific assets. For two assets the percentage of households who owned a specific asset was the same for both CD4 count groups. And for two assets the percentage of households who owned this asset was higher in the lower CD4 count group. However, if we then also look at the number of these assets that households own it can be seen that for 14 of the 15 assets, households with a respondent who started ART with a CD4 count of 200 and above, the average asset per household is higher than in the lower CD4 count group.

In Chapter 5 it was noted that on the whole households in Roma N’gome owned less assets than in Kalingalinga. Comparing the asset situation of household to CD4 count at start of ART in Kalingalinga provides us with a similar picture as was seen above. In Kalingalinga the majority (13 out of 15) of the assets is more often owned by households where the respondent started with ART with a CD4 count of 200 and above. Additionally the average number of assets per household is also higher (for 12 out of 15 it was higher, 2 it was lower, and one it was the same) in households where the respondent started with ART with a CD4 count of 200 and above.

The results in Roma N’gome are however far less clear. A possible reason for this is that there are less assets available in general to compare. Additionally the group sizes in Roma N’gome are quite small, particularly in terms of the amount of people who started ART with a CD4 count of 200 and above (n=10). There were 33 respondents in Roma N’gome who had a CD4 count of less than 200. In Kalingalinga there were 39 respondents with a CD4 count of less than 200 and 48 with a CD4 count of 200 and above.

### 7.3.2 Physical and mental well-being outcomes

In the previous section socio-economic indicators were looked at and current outcomes of these indicators were compared to previous situations. In this section a closer look will be taken at the physical and mental well-being of respondents. This will be, where possible, compared across the two geographic locations and over time.
Well-being
Respondents were asked to grade their life, with one being the lowest score and ten the highest. People were asked to grade their current life, their life at the start of ART, and their life before illness.

Figure 7.8: Respondents life scores of time

From the above we can see that the lowest scores were given at the start of ART. Additionally it can be seen that the highest scores were given before illness and currently: 87% of the respondents gave their life before illness a grade between 7 and 10 and 62% gives their life this grade currently. Before illness 3% graded their life between 1 and 4 and 10% between 5 and 6, currently this is respectively 11% and 27%. While currently people grade their life higher than at the start of ART they do not grade their life as highly as before illness. This can be seen from the table below:

<table>
<thead>
<tr>
<th></th>
<th>Before illness</th>
<th>Start ART</th>
<th>Current</th>
</tr>
</thead>
<tbody>
<tr>
<td>25th percentile</td>
<td>8</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Median</td>
<td>10</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>75th percentile</td>
<td>10</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>mean</td>
<td>8.72</td>
<td>5.42</td>
<td>7.34</td>
</tr>
</tbody>
</table>

Table 7.6: Mean and median scores for grading life over three periods.

In Chapter 5 it could be seen that there is a difference between people in Kalingalinga and Roma N’gombe in terms of how they grade their life and view their health status. This difference can also be seen across the three periods and is shown in figure 7.7.

<table>
<thead>
<tr>
<th></th>
<th>Kalingalinga Before illness</th>
<th>Roma N’gombe</th>
<th>Kalingalinga</th>
<th>Roma N’gombe</th>
<th>Kalingalinga</th>
<th>Roma N’gombe</th>
</tr>
</thead>
<tbody>
<tr>
<td>25th percentile</td>
<td>8</td>
<td>8</td>
<td>4</td>
<td>2</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Median</td>
<td>9</td>
<td>10</td>
<td>6</td>
<td>5</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>75th percentile</td>
<td>10</td>
<td>10</td>
<td>8</td>
<td>7</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Mean</td>
<td>8.53</td>
<td>9.08</td>
<td>5.89</td>
<td>4.65</td>
<td>6.86</td>
<td>8.14</td>
</tr>
</tbody>
</table>

Table 7.7: Mean and median scores for grading life over three periods in two areas.

While the same trend is visible as was noted above it can also be seen that respondents in Roma N’gombe grade their life currently and before illness higher than respondents in Kalingalinga. Additionally people in Roma N’gombe grade their life lower than respondents in Kalingalinga at the start of ART.
The group sizes for Roma N’gombe and Kalingalinga differ and the majority of the people in Roma N’gombe have a CD4 count of below 200 when they started ART. For the general health related question no missing values were found and as such the total 130 respondents for which the CD4 count is available can be used in the analysis below. In Kalingalinga 39 respondents had a CD4 count of below 200 and 46 of 200 and above. In Roma N’gombe 39 respondents had a CD4 count of below 200 and 10 had a CD4 count of 200 and above. The small number of people in Roma N’gombe who had a CD4 count of 200 is rather small.

Respondents were all asked about their general health at the time of the interview in 2012. Respondents were asked to choose the best category (Excellent=1, Very good=2, Good=3, Fair=4, or Poor=5) to explain their general health. In Chapter 5 we could see that people in Roma N’gombe reported higher general health outcomes than people in Kalingalinga. In Roma N’gombe the mean and median score for general health is “Very good” and in Kalingalinga this is “Good”.

<table>
<thead>
<tr>
<th></th>
<th>Roma N’gombe</th>
<th>Kalingalinga</th>
</tr>
</thead>
<tbody>
<tr>
<td>25th percentile</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Median</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>75th percentile</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Mean</td>
<td>2.21</td>
<td>3.1</td>
</tr>
</tbody>
</table>

*Table 7.8: Mean and median self-reported general health scores over three periods in two areas.*

In the graphs below the self-reported health outcomes of respondents were compared in the two locations in relation to the CD4 count respondents had when starting with ART.

*Figure 7.9: Self-reported health status by CD4 count in two locations*

From the above graph, in figure 7.9, we can see that respondents with a higher CD4 count at the start of ART currently also grade their health higher. This is particularly evident in Kalingalinga. The low number of respondents in Roma N’gombe with a CD4 count of 200 and above means we should view the above result, for Roma N’gombe, with some caution.
From the above table it can be seen that the mean scores are lower (indicating a higher general health score) for respondents with a CD4 count of 200 and above. Again the scores for Roma N’gombe should be viewed with caution seeing the low number of respondents who had a CD4 count of 200 and above.

A number of questions regarding physical health and mental health were asked. In Chapter 5 it was seen that in terms of physical health respondents in Roma N’gombe had comparable or less good physical health outcomes than people in Kalingalinga. At the same time it was also noted that people in Roma N’gombe reported to have better mental health outcomes than people in Kalingalinga. With similar or higher physical health outcomes it may have been expected that the self-reported health status would have been comparable or higher in Kalingalinga than in Roma N’gombe, yet the opposite was found. While it is not possible to compare the CD4 count level to the health outcomes of the respondent’s in Roma N’gombe it is possible for Kalingalinga.

A total of nine questions, with a 5 point Likert-scale, were asked regarding physical and mental health. These questions were coded so that for each question 1 would be the worst mental and/or physical health outcome and 5 the best. For each question the mean was calculated and this provided the following:

<table>
<thead>
<tr>
<th>Mean</th>
<th>CD4 count: 0-199</th>
<th>CD4 count: 200+</th>
</tr>
</thead>
<tbody>
<tr>
<td>My physical health has caused me to accomplish less than I would like</td>
<td>3.68</td>
<td>3.83</td>
</tr>
<tr>
<td>My physical health has limited me in the kind of work or other activities I perform</td>
<td>3.73</td>
<td>3.98</td>
</tr>
<tr>
<td>Emotional problems have caused me to accomplish less than I would like</td>
<td>3.38</td>
<td>3.73</td>
</tr>
<tr>
<td>Emotional problems have limited me in the kind of work or other activities I perform</td>
<td>3.59</td>
<td>3.79</td>
</tr>
<tr>
<td>How much did pain interfere with your normal work?</td>
<td>3.59</td>
<td>3.92</td>
</tr>
<tr>
<td>How much of the time have you felt calm and peaceful?</td>
<td>3.21</td>
<td>3.58</td>
</tr>
<tr>
<td>How much of the time did you have a lot of energy?</td>
<td>3.15</td>
<td>3.23</td>
</tr>
<tr>
<td>How much of the time have you felt downhearted and depressed?</td>
<td>3.59</td>
<td>3.75</td>
</tr>
<tr>
<td>How much of the time has your physical health or emotional problems interfered with your social activities?</td>
<td>3.68</td>
<td>3.96</td>
</tr>
</tbody>
</table>

Table 7.10: Self-reported physical health and emotional problems averages and CD4 count in Kalingalinga.
From the previous table we can see that for all questions the mean was found to be higher (thus a better mental/health outcome) for respondents who started with ART with a CD4 count of 200 and above than for respondents who started with a CD4 count of under 200. This indicates that both in terms of current mental and physical health respondents report more positive answers when they had a higher CD4 count at the initiation of ART.

The last results should be viewed with some caution. There were quite large differences found between Kalingalinga and Roma N'gombe in Chapter 5. In addition, most of the respondents from Roma N'gombe had a CD4 count of below 200 when they started with ART. As such, comparing mental and physical well-being outcomes for the whole group may cause for bias in the results. Additionally, the group size for Roma N'gombe is small and particularly the number of respondents with a CD4 count of above 200 is very small. As such, the analysis was only done for Kalingalinga.

7.4 Conclusion

In this chapter a number of socio-economic indicators and physical and mental well-being indicators were discussed. These were discussed in relation to the factor “time” and evidence was provided to see how current outcomes may be influenced by the past. The following questions were answered in this chapter:

- What were the personal characteristics and socio-economic status of individuals receiving ART before and at the start of ART?
- How do the personal characteristics and socio-economic status of individuals, and their household, before and at the start of ART determine the current well-being of individuals, and their households, receiving ART?
- How does ART affect the well-being of HIV positive individuals, and their households, who are receiving ART?

In the first section an overview was provided on when people started with ART and their physical situation at the initiation of ART. This included their CD4 count, whether or not they were bedridden, whether or not they needed assistance, and if they were still able to work at the start of ART.

In the second section an overview of some of the socio-economic indicators was provided and these were looked at over time and in relation to CD4 count and, where possible, location. In the third section the physical and mental well-being of respondents was discussed and, where possible, compared across the two geographic locations and over time.

General findings

Evidence was provided that a CD4 count of less than 200 went paired with higher chances of being bedridden, needing assistance and a lower chance of being able to work. Respondents in Roma N'gombe had, on average, lower CD4 counts at the start of ART. The sample of respondents from Roma N'gombe also included more people who had started in the early years of ART roll-out. As such, it is not entirely surprising that lower CD4 counts were found as the majority of the people who started with ART in the early years of ART initiation started with advanced stages of HIV infection.

Comparing employment over time showed that the situation before employment and currently on first hand looked similar. The percentage of PLHIV who were working for payment/profit had initially dropped to 27.2% during the period when people started with ART, but had been regained over time (before illness this was 67.5% and currently it is 72.8%). However, on closer inspection it was seen that while people were regaining their ability to work for payment/profit the type of work they are currently doing is not the same as they were doing prior to their
illness. The number of people working in formal and informal employment has decreased and the number of people now having their own business or doing piecework has increased.

The employment trajectories of respondents were discussed. In order to do this the employment situation of each respondent was compared over time: before illness to start ART, start ART to current, and before illness to current. From this it was seen that nearly 50% of the respondents who had been working for payment/profit prior to their illness had stopped working for payment/profit by the time they started with ART. This pattern was partly reversed after the start of ART where 43% of the respondents who were not working at the start of ART are currently working. Comparing the situation before illness to the current situation it can be seen that 52% of the respondents who were working for payment/profit before illness are currently also working for payment/profit.

The employment situation of respondents in Roma N’gombe and Kalingalinga is different. Far more respondents in Roma N’gombe (49%) are not working for payment/profit than in Kalingalinga (14%). Respondents in Kalingalinga are also far more often employed in formal (19%) and informal (33%) employment than respondents in Roma N’gombe (respectively 4% and 9%). A similar situation was found prior to the respondents’ illness where prior to illness respondents from Kalingalinga were more often formally or informally employed than respondents from Roma N’gombe. The number of respondents involved in formal and informal employment in Kalingalinga is currently almost the same. In Roma N’gombe we can instead see a stark decrease in the number of people who are currently formally or informally employed: before illness 12% of the respondents was formally employed and 23% that was informally employed, currently this is respectively 4% and 9%.

At the start of ART the employment situation of people in Roma N’gombe was worse than in Kalingalinga where 81% of the respondents in Roma N’gombe was not working for payment/profit at the start of ART compared to 68% in Kalingalinga. Additionally the type of employment that people were engaging in was, even, at the start of ART better in Kalingalinga than in Roma N’gombe: 20% of the respondents in Kalingalinga, at the start of ART, was formally or informally employed while in Roma N’gombe no one was formally employed and just 2% was informally employed.

In Kalingalinga 46% of the respondents is currently doing the same or similar work to what they were doing prior to their illness, this is only 24% in Roma N’gombe. Three times as many people in Roma N’gombe went from working for payment/profit prior to their illness to currently not working than is the case for Kalingalinga. The percentage of people who were working for payment/profit before illness and were able to continue doing so at the start of ART is higher in Kalingalinga (28%) than in Roma N’gombe (14%). After the start of ART people are expected to regain their health and in time should be able to return to work. This trend is visible, however, the number of people who were not working at the start of ART but have recovered and are currently working is higher in Kalingalinga (55%) than in Roma N’gombe (35%).

In conclusion, there were more people who initially were not working for payment/profit in Roma N’gombe than in Kalingalinga. Less people were able to remain employed in Roma N’gombe than in Kalingalinga. Additionally, more people also stopped working at the start of ART in Roma N’gombe than in Kalingalinga. Finally, less people in Roma N’gombe returned to work for payment/profit after they start with ART than in Kalingalinga. As such, people in Roma N’gombe not only have a worse starting position, they also appear to be able to recover less than people in Kalingalinga.

Comparing respondents’ CD4 count at the start of ART to their employment situation provides us with a number of observations. 66% of the respondents in Kalingalinga with a CD4 count of 200 and above were working both prior to their illness and currently, compared to 46% in Roma N’gombe. Respondents with a CD4 count of below 200 were also less likely to be working at the start of ART than people with a higher CD4 count. People with a CD4 count of 200 and above were also more likely to regain their employment than people with a CD4 count of below 200.
In terms of income it was seen that Roma N'gombe has lower mean monthly household incomes than Kalingalinga. Furthermore comparing income levels to CD4 count at the start of ART shows that household income is affected by the respondents CD4 count at start of ART. Respondents with a CD4 count of 200 and above currently have higher household incomes (€117) than people with a CD4 count of below 200 (€95).

Looking at the differences in household income level compared to CD4 count in Kalingalinga provides us with a similar trend. Average household income in Kalingalinga is higher where the respondent started with ART with a CD4 count of 200 and above (€122 compared to €108).

In terms of assets it was seen that households where the respondent had a CD4 count of 200 and above at the start of ART are more likely to own specific assets and on average own more assets than in households where the respondent started with a CD4 count of less than 200. This was also looked at for the Kalingalinga area where a similar result was found.

In terms of physical and mental well-being it was seen that people graded their life the lowest at the start of ART. The scores given currently have improved when compared to how they felt at the start of ART however remain lower than the scores prior to their illness. Comparing these quality of life scores between Kalingalinga and Roma N'gombe shows a similar pattern. However, respondents in Roma N'gombe give higher grades to their life currently (8.14) and before illness (9.08) than people in Kalingalinga (respectively 6.86 and 8.53). Respondents in Roma N'gombe instead give lower grades to their life at the start of ART (4.65) compared to respondents in Kalingalinga (5.89).

Respondents were also asked to describe their general health: people were asked to choose which category (Excellent=1, Very Good=2, Good=3, Fair=4, or Poor=5) best described their general health. The mean and median score for people in Roma N'gombe was very good (median=2, mean=2.21) compared to good in Kalingalinga (median=3, mean=3.1).

The general health scores were also compared to CD4 count for Kalingalinga and Roma N'gombe separately. From this it could be seen that respondents with a CD4 count of 200 and above reported higher general health scores than people with a CD4 count of less than 200.

A number of questions regarding physical health and mental health were discussed and compared to the CD4 count respondents had at the start of ART. In Kalingalinga we found that for all nine questions that were asked better mental and physical health outcomes were found for respondents who had started ART with a CD4 count of 200 and above.

Discussion
When people start with ART their physical health and the socio-economic situation, for both the respondent and the household, is often at its worst. People may have become very ill and have become increasingly unable to work. They may have lost their job at this stage and are in need of care. After starting with ART the situation is expected to improve and with time the physical health of the individual improves. People are able to return to work, become less and less in need of assistance, and slowly the situation for the individual and the household improves.

This chapter has provided an insight into the current socio-economic and physical and mental well-being outcomes of ART. It has looked at the trajectory that people go through and shown that the situation indeed first deteriorates (start ART) but then does improve. However, it was also seen that the current situation is not the same as it was before people became ill.
There are a number of factors that may influence the recovery of PLHIV on ART. These may be found by looking at how situations changed over time, what physical condition people were in at the start of ART, and in the opportunities that people have to recover what they have lost.

There is evidence that suggests that, in terms of physical health, for people who start with ART in the early stages of the HIV infection the recovery process will be quicker and that they will recover more fully than those in a more advanced stage of HIV infection. Medical evidence suggests that low CD4 counts at the start of ART reduce the chances of a full physical recovery. When people do not recover fully physically this also means that they will be less able to work.

In this chapter it was seen that people with a CD4 count below 200 at the start of ART were more likely to have lost their employment at the start of ART. They also less often recover their employment situation after starting with ART. Lower CD4 counts also led to lower incomes and households owned less assets.

While the trends appear to be the same in Kalingalinga and Roma N’gombe it should be noted that there are differences as well. The socio-economic situation of respondents in Roma N’gombe is lower than in Kalingalinga (see also Chapter 5). Not only prior to illness was the situation already worse than in Roma N’gombe but after the start of ART people were also less able to recover the socio-economic levels than people in Kalingalinga. This suggests that, while it is always hard for households to recover from shocks, recovery in Roma N’gombe is harder and people recover less.

Interestingly enough people in Roma N’gombe remain more positive in terms of the grade they give their life and how they view their general health than people in Kalingalinga. When looking at the start of ART people in Roma N’gombe instead graded their life lower than people in Kalingalinga. In Roma N’gombe respondents had lower CD4 counts at the start of ART than people in Kalingalinga. This result is somewhat surprising as it would be expected that a lower CD4 count also results in a lower current physical condition. However, returning to Chapter 5, people in Roma N’gombe have comparable or slightly lower physical health outcomes than people in Kalingalinga. In addition it was found that respondents in Roma N’gombe had a better mental well-being than people in Kalingalinga which may explain the above mentioned difference. With better support networks in Roma N’gombe than in Kalingalinga and people in Roma N’gombe to be amongst the first in Zambia to have started with ART their positive attitude may be partly explained.

Lower CD4 counts in Roma N’gombe indicate that the physical well-being at the start of ART was lower for the respondents from Roma N’gombe than for those in Kalingalinga. As such, people in Roma N’gombe faced, physically, a more difficult situation than people in Kalingalinga. The respondents from Roma N’gombe on average started with ART not only in a later stage of infection but also in the years that ART was first introduced in Zambia. As such, many of the respondents in Roma N’gombe were amongst the first people in Zambia to start with ART. Many people in Roma N’gombe will have faced a physical situation whereby they were bedridden and very ill. In addition, in the early years of ART in Zambia, HIV was still seen as a death sentence. Perhaps having been closer to death both physically as well as emotionally makes people from Roma N’gombe more positive today in comparison to people from Kalingalinga.
Chapter 8 – Towards a holistic understand of well-being

8.1 Introduction

The introduction of ART has changed many things, including the reality of many people’s lives. In the previous chapters some of the personal characteristics and socio-economic situation of PLHIV on ART and their households were discussed. In Chapter 5 an overview was provided of the current situation of PLHIV on ART and their households. Chapter 6 compared a number of personal characteristics and socio-economic indicators between 2010 and 2012 for a number of PLHIV on ART and their households. Chapter 7 provided an insight into how the trajectories that PLHIV on ART have gone through may differ. In this Chapter 3 time periods are looked at and factors that may influence the current well-being outcomes are explored. In order to fully understand the various trajectories and outcomes it is necessary to take a closer look at people’s actions. How do people understand the world around them, how do they deal with their situation emotionally, and what enables them or keeps them away from using resources?

This chapter is divided into two parts. In the first part of this chapter a closer look will be taken at how people value and influence the trajectories (from before illness to now) that they have gone through. A closer look will be taken at how people make sense of their HIV status and how they have dealt and deal with this emotionally. In this section the individual stories of PLHIV on ART will be discussed. The following research question was formulated:

- How do HIV positive individuals, and their households, receiving ART understand and experience their current lives, and how does this compare to their life before HIV and when they first started with ART?

In the second part of the chapter a closer look will be taken at how the different conclusions from the various chapters fit together and what this says about the interconnectedness of the theoretical framework. Through this a more holistic understanding of the well-being of PLHIV on ART and their households can be provided. The following research question was formulated:

- How do the different conclusions relate to each other and what does this say about the well-being of PLHIV on ART, and their households?

8.2 Trajectories

8.2.1 Introduction

In this section a closer look will be taken at a number of personal stories (all names mentioned in this chapter are pseudonyms). These case stories were collected for 161 respondents of which 10 were removed (for more information see: Chapter 3). However, not all of these can be discussed in detail here. Instead where this is relevant and possible references will be made to similarities or differences from other case stories.

The case stories that were collected for this chapter show a number of different trajectories. For the selection of these stories a number of variables were taken into consideration, namely: gender of respondent, location, employment situation (before illness, during illness, and currently), marital status, and CD4 count. These stories aim to provide an overview of some of the different scenarios and trajectories that people can go through. Many other stories exist next to the stories that will be presented in this chapter.
In the selected case stories a number of themes can be seen. The different themes will be discussed in this chapter and where possible linked back to the body, mind, and spirit framework that was introduced in Chapter 2.

### 8.2.2 The typical HIV story?

Before ART became widely available free of charge the ‘typical’ story of HIV ultimately ended with death. The coming of ART has changed this reality. Slowly but surely HIV is becoming increasingly accepted in society. In this research three stages were specifically looked at: before illness, start ART, current situation. Asking people to reflect upon the changes and trajectories that they have gone through reflect these periods.

While people do go through similar stages this does not mean that their stories don’t differ. How people experienced this period of illness differs. The degree to which physical health was affected differs. While some people report to have been bedridden and unable to work and even eat others report that their physical health was hardly affected and they were able to continue working. While some respondents received a lot of love and support from the people around them others report that they were discriminated, stigmatised, and even ostracised. Households have the ability to be a great safety net but also may fall apart completely: some of the respondents reported how they were supported and looked after by their families while other report that they suffered through divorces and were “chased” from their homes. Often people have spouses/partners who are also affected and in some cases households faced situations whereby partners were ill at the same time. As such, households are not affected in a uniform way. Moreover, the people and their social networks differ. The case stories presented in this chapter aim to show the differences, and similarities, that people face.

**Changing roles – How trajectories influence household position and role**

The following case story highlights the impacts of HIV on family demographics. The respondent goes from being a happily married housewife to a widow and the main breadwinner of a family of five.

"I can say I was very well before I contracted HIV. My health declined when I became HIV positive with a number of health problems including TB. But I can say I am back to my old self and once again happy and enjoying life." (30 year old woman from Roma N’gombe)

Before I was ill my life was good because I never used to face problems due to the fact that I was strong enough and I was able to do everything for myself and also my wife was very fit and my whole family was well. When I started to get ill everything started changing bit by bit things were getting harder and I was becoming very weak. I had some black spots on my face. Now that I have gotten used to the drugs and I regained my health and now I am very fine. (40 year old man from Kalingalinga)

"I was alright and all was well before I was ill, but things changed when I started to fall ill up to the time I was discovered to be HIV positive and put on ART. I was not able to do most work during my illness until sometime after being put on ART when my life started to improve. Now I am ok and I am able to do almost all work without help." (49 year old man from Roma N’gombe)

"I went through three phases. When I was well I enjoyed good health and marriage. When I fell ill I was deserted, stigmatised, and ostracised until I started ART and started recovering slowly. Now my life is back to normal. I am married again with 3 lovely children. I work and contribute to the upkeep of my family. I do all normal daily household chores." (35 year old woman from Roma N’gombe)
The above story provides an insight into how multiple people in one household can be infected and how this impacts the household as a whole. Clearly, the role and position that Hope had in the households before her...
illness, is not the same as she has today. Hope however shows incredible resilience and has managed to secure a job as a maid.

Hope discovered she was HIV positive because her husband became ill. Hope started with ART a month after she was tested and not immediately like her husband. From this and from Hope’s comment about her health we can conclude that her health had not yet deteriorated as much as that of her husbands. Hope’s husband was very sick when he started with ART and he passed away shortly after he started with ART. Hope lost her husband at a time when she herself was starting ART and was suffering from side-effects. The impact of losing her husband, whom she reports she had a good life and marriage with, will have added to her emotional distress at this time.

When Hope started with ART she suffered from a number of side effects. In addition, shortly after she started with ART she also discovered that she had Tuberculosis (TB). From the case story we can see that Hope shared the news about her HIV status with her relatives. She reveals that her relatives were not happy but that they did support and encouraged her to continue with the medication.

Individuals deal differently with the news that they are HIV positive. The news typically has severe impact on the emotional well-being of the individual and his/her family. Many emotions come paired with this news, such as denial, fear, and hope. In the body, mind, and spirit model the emotions and aspirations of an individual are seen as the spirit. The mind instead is related to the beliefs that the person has and finally the body refers to the physical health.

Hope explains that when she first learnt that she is HIV positive she is very worried about the fate of her children. She further explains that when she started with ART she was very sick and she was worried that she would die and would leave her children behind as double orphans. At this moment Hope’s physical health (body) is severely affected. She believes that she will die soon (mind). And finally she is worried and stressed about the fate of her children if she dies (spirit).

Leaving behind children and worrying about their future is a common theme. It is not only a worry for many people, particularly for women, but also a motivational factor for people to try everything to get better. Hope reports that when she starts with ART she is afraid that she is going to die. Her husband recently died before this and he was also on ART, it is as such not entirely surprising that Hope too fears that the same fate awaits her. In addition, she is suffering from a number of side effects and her physical health has been severely affected. Clearly Hope desperately wants to get better and continue looking after her family. She is supported by her family who encourage her to take the medication and tell her that the medication will make her feel better.

Finally Hope explains that the side effects she was suffering from have all disappeared now and her health has improved. She is now working as a maid and earning an income to support her family. She explains that her children assist her where they can.

The trajectory that hope went through is in a sense ‘typical’ – she went from a period of good health, then through a period of bad health, and has now regained her strength. However, it also shows that within this trajectory many other things can happen and play a role. If Hope and her husband had known about their HIV status earlier and her husband had started with ART earlier he may still have been alive today. If Hope’s relatives would not have
been as supportive it is uncertain if Hope would have continued with her medication. And finally, as Hope rightly asked, what would have happened to Hope’s children if she would have died?

Many things have changed for Hope; she is now living with HIV and will need to continue taking drugs for the rest of her life. In addition, she is now a widow; she has become the head of the household and is the breadwinner for the family. Hope was not employed before she became ill, instead the family depended on Hope’s now deceased husband. She now works as a maid. Hopes physical strength (body) has improved. She no longer believes she will die and says she is open about her HIV status (mind). Hope does not experience any stigmatisation and she even teaches (about HIV) in the community. Comparing her life now to how it was when she first started with ART we can see things have improved (spirit).

*Early discovery – the impact of early discovery*

The next case story is an example of a situation where the period of serious illness is missing.

**Case Story: Early discovery**

Sarah is a 43 years old woman living in Kalingalinga. She is married to John who is 49 years old and together they have a daughter called Thandiwe who is 3 years old. Sarah tested HIV positive in 2008 and started with ART soon after she tested positive. Sarah, John, and their daughter Thandiwe live in a rented house. The house they rent is relatively good for this area and they have electricity and running water inside the house.

Sarah works as a pre-school teacher and John works as a carpenter. Their daughter Thandiwe is attending pre-school.

Early November 2008, Sarah went to the clinic. Sarah was pregnant and was going to for antenatal care. At the clinic they tested her for HIV and the results of the tests showed that she was HIV positive. The results surprised Sarah. She says that she went home after this to share the news with her husband; he too was surprised at the result. The news was hard on both Sarah and John but she says that “we managed to accept the situation after some time”. Soon after Sarah discovered she was HIV positive she started taking ART, when she started her CD4 count had dropped to 208.

Sarah explains that while her CD4 count was quite low she never became bedridden, didn’t need any assistance, and never had to stop working. She continued working as a pre-school teacher, as she was doing prior to her illness, and still does today. During the period leading up to her starting ART she lost some weight and she explained that she suffered from diarrhoea. The weight loss and diarrhoea made her feel weak and tired. “When I started ART my life was well, only that I used to have diarrhoea at times, but as at now my CD4 count has raised to 580 and I feel good, I don’t have any problem in working for myself, I have gained weight, I was weighing 59 kg, now I am 75 kg.”

Sarah explains that before she was ill “My family was perfect, I was happily married”. While both she and John were shocked to discover that she was HIV and they experienced some difficulties, they have managed to stay together: “We are happy together. And I am happy that I am still married to the same man as before this illness, the father of my child”.

Today, Sarah says, her life is much the same as it was before her illness and she explains: “My CD4 count was raised, it is high now, and I can eat and do work for myself. I still work, as before, as a teacher. The drugs have done me good and I am much better”. She furthermore explains that if she has to compare her life to when she first started with ART to how it was before or how it is today that “Nothing much has changed. Only that I don’t have a runny stomach anymore and I can eat freely.”
Sarah’s story describes a situation whereby no period of serious illness is included. Sarah’s physical health (body) was affected but not to the extent whereby she needed to stop working. The early discovery of her HIV status was due to the fact that she was pregnant; all women who go for antenatal care in Zambia are automatically tested for HIV\textsuperscript{101}. Because she discovered that she was HIV positive before she became seriously ill she was able to start with ART early – this has ensured that her physical health never deteriorated drastically and has resulted into her child being HIV negative.

After Sarah discovered she was HIV positive she shared this news with her husband. She explains that the news was hard and came as a shock but that both she and her husband accepted the situation. Sarah and her husband are still married today and she explains that they are happy together. Sarah and her husband appear to have supported each other through this difficult period in their lives. From the story we can see that Sarah has a positive outlook and she and her husband are doing well.

Comparing her life today to how it was before she discovered she was HIV positive she explains that “nothing much has changed”. She mentions that she is happy that she no longer has problems with eating and has gained weight. Seeing that Sarah never stopped working or became very ill the households was not placed under severe strain economically. Sarah immediately accepted to start with ART and through Prevention of Mother to Child Transmission (PMCT) also protected her child. She never went through a stage of denial or fear that the drugs would not work. Instead she reports that the main benefits of the drugs were that her child is HIV negative. Sarah was as such emotionally supported (spirit), had belief in her life and that the drugs would make her better (mind), and finally her physical health (body) remained relatively good throughout.

Taking medication in order to protect your child or to ensure that you can look after your child(ren) in the future is a common theme, particularly amongst women. When asking respondents what the main reason was that they started with ART, particularly amongst women, the future care for children is amongst the reasons mentioned. Similarly when asking people what they feel are the main benefits of ART some mention that it has allowed them to live longer which enables them to look after their children.

\begin{quote}
“\textit{I wanted to be well; someone needs to be looking out for my children.}” (43 year old woman from Kalingalinga)
\end{quote}
\begin{quote}
“\textit{I wanted to improve my health so that I can live longer to see my children grow up.}” (36 year old woman from Roma N’gombe)
\end{quote}
\begin{quote}
“\textit{Fear of death and worrying about my family became my preoccupation.}” (54 year old man from Roma N’gombe)
\end{quote}
\begin{quote}
\hspace{1cm} “\textit{To find prolonged life so I can look after my children.}” (45 year old woman from Kalingalinga)
\end{quote}
\begin{quote}
“\textit{I wanted to get better! I did not want to remain sickly and eventually die – leaving my children destitute.}” (56 year old woman from Roma N’gombe)
\end{quote}
\begin{quote}
“\textit{I never wanted to die early and I still want to look after my children.}” (29 year old woman from Kalingalinga)
\end{quote}
\begin{quote}
“\textit{Life has been prolonged, I am able to work and I am looking after my children}” (45 year old woman from Kalingalinga)
\end{quote}
\begin{quote}
“\textit{It has improved my health and given me a chance to see me children grow up.}” (50 year old woman from Roma N’gombe)
\end{quote}
Sarah explains that her husband and she accepted the situation after some time and that she quickly started with ART. Many of the respondents talk about acceptance. Early discovery can lead to people starting with ART before their health has been (severely) affected. Encouragement from others and wanting to get better are often mentioned as reasons for people to accept their situation and start with ART.

“When I informed my husband about my VCT results he encouraged me to accept the situation. And I then decided to start with ART” (34 year old woman from Roma N’gombe)

“In the same year in November I became very sick and my husband took me to the hospital and it was discovered that my CD4 count was very low and they advised me to start ART by the doctor and failure to start then that means I will die very early. I never wanted to die early, that’s why I had to accept the treatment of ART.” (31 year old woman from Kalingalinga)

“The family those days was just okay; they accepted me and helped me to keep strong the way that I responded to the treatment I never used to sleep much, also feeling too tired. And my CD4 count was 334. I trained myself to accept that I was living with HIV and taking drugs for the rest of my life.” (43 year old woman from Kalingalinga)

“Because I really accepted my situation I did not encounter a lot of problems, so it did not take long after I started taking ARVs before I was almost back to normal, the recovery was meteoric (rapid/fast) I can say.” (45 year old woman from Roma N’gombe)

From the above quotes we can see that people do accept the situation, although this may not always be easy. In the last quote the respondent explains that by accepting the situation and starting with ART as soon as she could she managed to avoid becoming sick and had a speedy recovery. However, it should be noted that acceptance can take time. This is often a difficult process and is experienced differently by people. Some people, as was seen above, decide that the only way forward is to quickly accept and continue with their lives while others report that they were in denial and did not accept that they were or could be HIV positive. For some people this period of acceptance is a few days while others take months. In a few cases people only accept to start with ART when they are near death. Some respondents, as was seen in the Sarah her case story, received support from their families while others lost their partners because they refused treatment.

“I was told that I was HIV positive and I couldn’t believe it. And not until I requested for another test, and it came out the same, that I believed that I was truly HIV positive. My CD4 count was very low and I was told to be on ARTs instantly because it was already too late”. (31 year old woman from Kalingalinga)

“It was in 2007 when I started feeling unwell. My weight went down, but I had no pain anywhere in my body. I went for VCT and was told that I was HIV positive. I did not accept the result and went to two other places for confirmation. All three results came out positive. I was in denial and started getting worse. My condition deteriorated so much that I had to be admitted to Chelstone Clinic in a moribund state.” (31 year old man from Roma N’gombe)

“This was after two years of marriage. This is the time my husband talked about his status for the first time. It was a very big shock for me. I asked him to take me for VCT and this is where they found that I was HIV positive. By this time my CD4 count had already dropped to 150. This disease had already entered my body and very hard for me to accept. I first didn’t want to take the drugs because I didn’t accept I was positive. The whole situation made me hurt him and hurt myself. I was very angry that I had not gone for VCT before I had married him.” (37 year old woman from Kalingalinga)
From the above quotes it can be seen that accepting that you are HIV positive and accepting treatment is not straightforward. It may take time for people to come to terms with the situation. Unfortunately when people delay with starting with ART this can have devastating effects. In the quotes above we can see how one man continues to refuse his status even after he has been tested HIV positive three times. Only when he is hospitalised is he put on ART. Other respondents even report that their spouses ultimately died because they did not accept their HIV positive status and refused treatment.

Stories wherein women explain that their spouses have died because they did not accept treatment are not uncommon. There appears to be a lack of self-awareness about HIV amongst men, when compared to women. This is illustrated in the last two quotes wherein couples are found to be HIV positive and only the women starts with ART while the man refuses and as a consequence dies.

In the above quotes it can also be seen that people mention “self-stigma”. Self-stigma is a common problem whereby many people feel that they have done something wrong, that they are now worth less because they are HIV positive, and that because of their status there is no hope for the future. Understanding that one suffered from self-stigma is often achieved through counselling whereby the person comes to terms that he/she is HIV positive. The fact that it is mentioned by respondents, more frequently by people from Roma N’gombe than from Kalingalinga, is illustrative of them having had counselling and support.  

**HIV before ART – changing realities**

The two case stories that have been discussed describe situations wherein ART is readily available. ART was not always readily available in Zambia. Before ART became available many people died and the disease was looked at in a very different way. While ART and the situation wherein it is possible to continue living with HIV is now increasingly becoming part of society, this was not always the case. Before ART was introduced many people equated HIV with death and stigmatisation was very rife. Stigmatisation today still plays a role and particularly when people are ill they suffer from stigmatisation.

The next case story is about a woman who knew she was HIV positive before ART was available. She is amongst the first few people who were put on ART in a pilot project in Lusaka.
Case story: Living with HIV for more than one decade

Beatrice is a 31 year widowed old woman who lives with four of her children in Roma N’gombe. Beatrice never attended any form of school. Her oldest child Collins is 17 years old, he stopped school after completing primary school due to a lack of finances. Conwell is 6 years old and is currently attending pre-school. The youngest two children Cynthia, who is three years old, and Emma, who is 2 years old, are still too young to go to school.

Beatrice and her children live in a rented house in Roma N’gombe; the house has no access to water or electricity. Water needs to be fetched from a public tap. Beatrice has no job and is dependent on any type of piecework that she is able to find. She explains that she mainly washes clothes for a fee for people in Roma N’gombe. The average monthly household income is said to be 200,000 Kwacha (~€31).

Beatrice her story starts in 1994 when she met her first husband: “In 1994 I got married to my first husband, I was 14 at the time. We got married because I got pregnant. My mother died when I was 1 year and 6 months and I was sent to go and live with my mother’s younger sister. While I was living there I went to visit my grandmother in Chongwe. It is in Chongwe where I met Conwell, my first husband, and I got pregnant and then got married because of that. We left Chongwe after some months to come to N’gombe, we lived here together for 7 years. That is now 12 years ago. My first husband passed away in 2000. I became a widow at 21”.

Conwell and Beatrice had three children together Collins, Catherine, and Joshua. Asking Beatrice how she came to know that she was HIV positive she told the following story: “The problems started when my baby [Joshua] started to get sick, so we went to the clinic and found that he had Tuberculosis. They put him on Tuberculosis treatment but he was not getting better, he remained ill and we saw no improvement. That is when we were advised to go for VCT, so me and my baby went for VCT. This is where we discovered that both me and my baby were HIV positive. My CD4 count at this time was 140 and that of my baby’s I cannot remember. This was in 2001. In 2001 there were no ARVs, and because of that my baby died”.

Beatrice continues: “When I heard that I was HIV positive I became very worried and I started to think that I would die soon. My family stigmatised me, they wanted nothing to do with me. I felt they were laughing at me and they were saying that I would die soon. My children were not allowed to eat with them or their children out of fear that they may pass on the disease. During this HBC registered us so when the ARVs became available in a pilot programme in 2004 I was immediately put on ARVs. I was sickly for more than two years before I could start with ART. At that time I also could not work. I was very ill. I tell you that it is because I was cared for so much by my sister with whom I used to live and the same people here at the HBC. My CD4 was 150 and I was very ill. Before I started ART I was very sick, my whole body was sick, I was coughing, had diarrhoea, headaches and I was always cold.”

“After I started ARVs my health started to improve and I started to look better again about 5-6 years ago. This is when I met another man, his name was also Conwell. We got pregnant and he then ran away. I had not told him about my status but he found out anyway, he became scared of the funeral expenses. He was told by someone that the child and I would die. I have heard that he has passed away.” Conwell and Beatrice have one child together, the child is named Conwell.

“After Conwell I met George, I have two children with him. But I do now know where he is now, after I got pregnant the first time he became sickly and went to his mother in Mpika. He returned later and I again got pregnant. He was also HIV positive and he was taking ARVs. He never supported me, he was always running away. He has now passed away.”
Looking back at how things were when she started with ART and how things are now she says: “I have power again and I am able to work. Eating food is no longer a problem and I don’t have to vomit every time I eat like the way it used to be. Also my legs are now much better. My family sometimes just wonder how it is possible that I am still alive, everyone expected me to die. I am now okay, I can work and even do some piecework so that I can also buy some things myself and don’t need assistance for everything. Also I am still on the same medication that I started with. In March they changed my medication but I did not respond well and so they returned me to the previous medication.”

Finally, the changes that have occurred in her life are discussed, and Beatrice says: “I was fine before I became ill. I was strong and I could do any kind of work. Everything was fine and I as working and I had money. I had a lot of power and strength in my body and I was able to eat anything. I was working for payment and I was happily married, we had no problems. After my husband died and I gave birth all the problems started. I too started to get sick. I was weak, vomiting, I lost weight, had numbness in my legs. But before all of this everything was just okay. When I started with ART everything was hard. I was not eating, not working, vomiting all the time, legs were numb, I needed assistance with everything, I was not having sex without a condom. But now my strength has returned a bit and I can do some work.” She further reflects on how her life is now compared to how it was before she was ill and says: “There is a change, because before I was ill there were no problems. Everything was fine. I was working and buying everything I needed and wanted. But now my life is not fine, not like it was before. Everything I want to do now has a limit. You can’t do this and you can’t do that. Today you might be alright, but then tomorrow suddenly you are not. Everything is limited and with everything you have to pay attention to your limits. For sex you now need to wear a condom.”

Beatrice’s last CD4 count was 1002 cells per cubic microliter.

The case story of Beatrice is quite unique in some ways while in other ways bears great resemblance to the story of many other people. Beatrice is amongst the first people to have started with ART in Zambia. She already had a rather low CD4 in 2001 and this was still low in 2004 when she started with ART. Despite this her current CD4 count is very good and what we would expect in an uninfected person.

Beatrice and her family have a very low income and no one in the household has a job. Beatrice and her four children are fully dependent on the piecework that Beatrice is able to find.

When Beatrice was 14 she fell pregnant and she got married. After just seven years of marriage her husband passed away, leaving her with three children. The youngest child was just a baby by then and soon after became sickly. Both Beatrice and her baby were found to be HIV positive in 2001. Beatrice explains that because there were no ARVs available at that time there was nothing that could be done and her baby died. The death of her husband and the death of her baby were the end of Beatrice her life “before illness”. At the age of 21 Beatrice became a widow, was found HIV positive, lost one of her children, and was left to look after her remaining two children alone.

From the case story it can be seen that when reflecting on her life Beatrice has gone through very difficult periods and even today she feels that life is less good than it was before she became ill. Reflecting on her life before she became ill Beatrice explains that everything was fine before, she could work hard, her physical strength was excellent, she was employed, and she was happily married. All in all she concludes that before she was ill she and her husband had no problems. Beatrice explains that the ART have restored some of her strength and she is able to work a bit. However, things are not fully restored: “before I was ill there were no problems. Everything was fine, I was working and buying everything I needed and wanted. But now my life is not fine, not like it was before”.

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After Beatrice started with ART her health improved. After recovering physically she meets another man and
became pregnant. Beatrice does not share with him that she is HIV positive and after he finds out he leaves her.
Beatrice explains that he leaves because he is afraid that she and the child will die and that he is afraid of the
costs that are related to this. Later on she meets another man, he too is HIV positive and is on ART. From
Beatrice her account we can see that neither of these two men supported Beatrice or their children with her. Both
of them, according to Beatrice, have now died.

During the time the Beatrice was sick she suffered a lot of stigma. She explains that her family stigmatised her
and “wanted nothing to do with me”. She explains further that she felt that they were laughing at her and that they
too expected that she would die soon. The stigma was not only directed at Beatrice but also at her children. The
children were not allowed to eat with the other children out of fear that they may pass on the disease.

Stigma and the fear of dying are still common themes today. There are many forms of stigma and many reasons
why people get or feel stigmatised. Beatrice tells us that her family stigmatised her and that they thought she
would die soon. When ART was not available in Zambia a lot of people did indeed die and HIV was seen as a
death sentence. This and a lack of knowledge regarding the disease and how it spreads made a lot of people
afraid of it. Fear of death and fear of getting infected and dying yourself, may be a source for stigma. Many
people who found out that they were HIV positive feared that they would die soon, and many of their relatives,
friends, and neighbours shared this fear.

In the following quotes are a few examples of how stigmatisation goes paired with death. In these quotes people
describe how they were stigmatised and how the same people who stigmatised them also told them they would
die soon.

“I was stigmatised when I was sick, people thought I would die. They would ask me what I was going to do.” (31 year
old woman from Roma N'gombe)

“I was seriously stigmatised by my aunt. For example, my HIV positive son and I were given our own utensils to use.
Some family members stigmatised me a lot and said that I would die." (42 year old woman from Roma N'gombe)

“I became very sick towards the time when I was about to start taking ART. That's when things became worse, and
people they even started laughing at me saying I was going to die very soon. They would tell me that I would be
leaving the world. I used to suffer from this and I really hated it when people told me these kind of things and using
those words.” (29 year old woman from Kalingalinga)

Stigmatisation and the fear of death also cause a lot of emotional distress for people. Earlier it was seen that
people were very worried about the fate of their children in the event that they would pass away. People who are
stigmatised and become isolated may also become more depressed. They may feel like people have given up on
them and they have just been left to die. In the following comments the emotional distress that many people
suffered through due to stigma and their fear of dying.

“My life was miserable. I experienced a lot of stigma and ostracism from my mother and siblings. My husband
deserted me and my child. I was feeling unwell and had no one to care for me. I was afraid I was going to die.” (35
year old woman from Roma N'gombe)

“The fear of death and the stigma that came with this also made me feel low most of the time.” (56 year old woman
from Roma N'gombe)
From the above quotes it can be seen how the stigmatisation that people faced caused them a lot of emotional distress. The respondents mention that they have lost hope and feared that they would soon die. The period when people start with ART is clearly a difficult period for most. Not only is it at this time that they are faced with the emotions regarding their HIV status but their physical health is often at its lowest point. After testing HIV positive people are faced with the question regarding disclosure and how people will react to this news. From the above quotes we can see a number of examples on how people’s relatives and spouses reject and stigmatise them. Being rejected and stigmatised by their own family will further increase the emotional distress that people are facing. Feelings of being alone, feeling deserted, and stigmatised while also physically feeling unwell can lead to people feeling depressed, hopeless, and even afraid – afraid of death.

In the case story of Beatrice it was seen that her relatives too feared she would die soon, Beatrice even explains that the same relatives continue to be surprised that she is still alive. As was explained previously, when Beatrice became ill there were no ARVs available in Zambia. During this time many people indeed did die. This reality has changed but is still very much present in the back of people’s minds. This is explained in the following quote.

“It was believed some years back that if you are HIV positive you will soon die. That made me afraid and I was not comforted by my family. I became ill and afraid of dying because my family had rejected me.” (50 year old man in Kalingalinga)
Not everyone who starts with ART reacts well and side-effects often occur. Additionally there are still cases whereby people start with ART in a very advanced stage of HIV infection. Starting with ART at a late stage of HIV infection increases the risk of morbidity and mortality. When people who are on ART die, this can impact the way that people view ART. The following quote demonstrates this.

“When I started ART I was very scared that I was going to die especially if I hear that someone on ART had died. I felt very depressed and thought that I was next in line to die. I was bedridden, weak, no appetite. My CD4 count was very low and I suffered from all sorts of infections. I lost weight and was stigmatised.” (51 year old woman from Roma N’gome)

In the previous quote it can be seen how hearing about PLHIV who have died even though they were on ART can cause great worry and concern. After all if this drug didn’t work for them then why should it work for me?

When people do believe that ART may prolong their life then this knowledge in combination with (the fear of) stigmatisation and the fear of death can actually encourage people to seek help. This is demonstrated in the next quote.

My life was not good at all and that’s why I started taking ARTs earlier. I was facing problems like not enough blood in my body. I started slimming whereby people started laughing at me and saying bad words about me. They were also definitely concluding that I was HIV positive, even though I did not even tell them! Actually that’s also a reason why I started ARTs because I wanted to get fat in order to avoid people laughing at me.” (35 year man from Kalingalinga)

The above quote demonstrates how people can also be motivated to start with ART in order to avoid becoming ill and further stigmatised because of this. Knowledge and believing that ART can improve your physical health (mind) as well as a positive attitude and mental strength to act (spirit) can lead to early initiation of ART and this in turn can lead to improved physical health (body).

Support and love – the impact of support
Support of family members, partners, and friends can have an enormous impact on the well-being of individuals. When people are supported, loved, and cared for when they are sick and when they discover their HIV status this can make the process of acceptance and recovery far easier. While stigma and rejection is a real reality for many people the opposite is also possible. The next case story describes a situation whereby the respondent was loved and supported by his family.

Case story: Support and love
James is a 40 year old man living in Kalingalinga. He is married to Miriam who is 47 years old. Together they care for three children. The oldest, named Jack, is 15 years old and is their biological child. They also care for Sam’s nephew of four, named Phillip, and his niece of two, named Mary. Phillip and Mary are double orphans. Both Phillip and Mary are HIV positive and are on ART.

Both James and Miriam have completed secondary school and had some formal training after this. James works as a security guard and Mary is a receptionist. Jack is in Grade 9 and attending school on a full time basis. The two younger children have not yet started school; James explains that they are still too young. The family owns the house that they are living in; the house has access to electricity but the family needs to collect water from the public tap outside of the home. The family’s monthly income is around 1.2 million Kwacha (~€185).
Before James became ill he had a different life from the one he has now: “At that time I was working as a train monitor at the Zambian Railways in Kabwe. I mean, at that time I was a real man! [James laughs at his own comment] My house was nice looking! At that time we were provided with accommodation by work and I have to tell you that it was wonderful!”

Things started to change for James when he started to become sickly: “I started to feel unwell; this was when I was still working as a train monitor but now in Kitwe. And then my health started having complications. When I went to the clinic they found that I had Tuberculosis”. Because of his deteriorating health and because of his Tuberculosis James lost his job as train monitor: “I was forced to lose my job due to this illness. Even after four months of being on treatment I could still not recover as I was not responding well to the treatment. I was then advised to go for an HIV test. I went to take the test and the results came out positive. I then became bedridden and I had so many different pains in my body. Almost each and every part was in pain. This is when I was put on ART. By then my CD4 count was 170. By this time I was married and we had one child together”.

James continues to explain what his life was like when he started with ART: “When I started with ART things were no longer the same. My life became so difficult. I was bedridden, I could not work and do things for myself, and I was just being helped. It was my wife who was helping me; she has been there for me always. There were also just too many drugs, too many for me to take! There were those for Tuberculosis and then there were the ARVs as well. It was a big burden for me. I tell you, my friend, I was almost dying! I couldn’t even eat, my food intake was like a disaster”.

When James was sick his wife continued to work as a secretary, through this she was able to support the family financially. As mentioned above, Miriam stood by her husband during his illness and assisted and cared for him, James explains: “I was weak and could not work. I really could not do anything on my own, not even bathing myself or eating. It was my wife who helped me through everything in this time. She never neglected me and was always there for me. Even today, I appreciate her so much.”

Looking back and comparing the current situation to how things were when he was ill James says the following: “when I started ART I was going through hell, but now I am doing much, much better. I am able to work and my strength is back. I am now working again, though I now work as a security guard. Thankfully I am able to eat normally again and I no longer feel stressed. I am enjoying life and I take myself as I am. My CD4 count has raised to 467. I also don’t face problems with other people and I am not scared about people finding out about my status. Actually what I can tell you is that most of the people around me are in the same situation with this condition. Finally I must say that ART has helped me tremendously in terms of becoming who I am, in fact it is because of ART that I manage to talk to you today.”

From the above case story it can be seen that James has gone through a difficult and long period of illness. Throughout his story it can be seen that James was supported, encouraged, and loved by his wife. James lost his job and was physically very ill, he became completely dependent on others. This case story is an example of how important support, encouragement, and love is for PLHIV. James’s attitude is very positive and filled with hope. And while he went through a very difficult period he realises that this period was made much easier through the support and love he received from his wife. Accepting ones status, recovering from illness, starting and adhering to ART, and having hope for the future can be made much easier for people when they have a network of support around them.

There is nothing in James his story to suggest that he was stigmatised or rejected by his family or by people in his surroundings. He is open about his status and is aware that he is not alone – there are many people in his surroundings who are HIV positive too. He has a positive attitude towards life and even though he may miss part
of his previous life he is looking forward rather than reminiscing about what he once had. Having a support system can enable people to take a positive attitude towards life. By not being rejected people may also become more open about their HIV status. Through being open people also find support outside of the household and avoid becoming isolated. Not being the only person who is HIV positive but by seeing others who are in a similar situation can help people in accepting their HIV status.

Encouragement and a positive attitude is a very important for people to be able to accept the situation. While stigmatisation is present in many stories, many people also report the love and encouragement that they experienced when they were ill. Particularly when it comes to accepting the situation, realising that you are not alone, and taking medication people reported that some people in their surroundings encouraged them.

*“My mother encouraged me to look for where we could access ARVs she even counselled me. So she took me to Chingwere clinic to see if we could find ARVs (32 year old woman from Roma N’gombe)*

*“My mother told me that taking these drugs hasn’t started with me alone that there are many people who HIV and that I should just continue taking the drugs all the time.” (32 year old woman from Kalingalinga)*

*“After some days I disclosed it to them [her family] and they showed some sadness, though they realized I was going to get more worried so they accepted the situation and encouraged me to be strong.” (42 year old man from Kalingalinga)*

*“My mother encouraged me to continue taking my tablets.” (51 year old woman from Roma N’gombe)*

*After I started ART I decided to tell my eldest daughter about my status and the medication. She never said anything; instead she always encouraged me to take my medication. She was supporting me so much.” (60 year old woman from Roma N’gombe)*

*“When I informed my husband about my VCT results he encouraged me to accept the situation. (34 year old woman from Roma N’gombe)*

*My parents died and I started staying with my auntie. She used to encourage me to take my drugs. She gave me the care that I needed and told me to be just myself and that everything was going to be alright. She tried by all means to make me happy. (19 year old woman from Kalingalinga)*

*My mother always encouraged me and told me not to worry. She encouraged me and told me not to think about it. Instead she told me I should focus on the fact that I was pregnant. (47 year old woman from Roma N’gombe)*

Encouragement can come from different people some are encouraged by their spouses whilst others find love and comfort from their children. Many people later also start offering the care and support they received when they were ill to others in the community. By supporting others and sharing their experiences people find means to deal with their own situation. This is done both in support groups and counselling sessions but also directly in the community, amongst for example neighbours or friends.

*Marital problems – living positively and making changes*

In the next case story it can be seen how a marriage can be placed under severe pressure when people first learn they are HIV positive. It also shows how support does not always come from within the family and that stigma is often paired with the period of illness.
Case study: Marital problems

Godfrey is a 45 year old man who lives with his wife and two children in Kalingalinga. He works as a gardener and is the main breadwinner in the household. His wife, Joyce, is 39 years old and sells goods at the market to supplement the household income. Their two children, Kennedy of 19 and Hope of 10, are attending school. Kennedy is in his final year of secondary school and Hope is in Grade 4 at primary school.

The family lives in a rented house in Kalingalinga; the house has access to water from a tap in the yard but has no access to electricity.

When asking Godfrey about his life story and about HIV he proclaimed: “Well, my life history was not as good as one would think”. He continues to explain how he discovered that he was HIV positive and the events that led up to this. “I started feeling bad in 2009. I was just feeling like I had malaria, I then started having a runny stomach [diarrhoea]. At first, I treated it myself with some traditional medicine. The malaria and my runny stomach then stopped for a short time but it soon started again. At the time this happened I used to work as gardener in Jesmondine, just over there in Munali [Jesmondine is a section of Munali, it is a 45 minutes’ walk from Kalingalinga]. Then, in March of that same year, the problem of the stomach came back and that time I also had herpes-zoster (shingles). It was so painful and this caused me to be very angry. At this time my wife took me to the clinic. At the clinic they were asking me a lot of questions. Some of the questions I could not speak freely about, especially not while being in the same room with my wife where she could hear the answers. Then, later on, after all these questions this clinical officer just told me to go for VCT. We went for the test together and the results came out positive for both of us.”

The news affected Godfrey and the family severely and caused a lot of tension between Godfrey and Joyce. “My wife was so upset that from there onward she started sleeping alone. She also stopped cooking for me that same month that we started taking the drugs. However, the situation became even worse. My wife would insult me whenever she wanted. That’s when I just thought that I should just overdose myself so that I would die.” He goes on to explain the situation at home at this time: “At first my wife was good, she used to help me with feeding and bathing but eventually she just changed and started insulting me that I was useless to her and at work my boss told me to stop going for a while. So things went bad for me because she would cook food and then not give me anything to eat, telling me that I am the one who has made her sick.”

Godfrey started ART with a CD4 count of 50 he reports that he was bedridden, was unable to work and needed assistance with even the most basic tasks such as bathing and eating. The situation at the start of ART is described by him as follows: “When I started ART I had herpes-zoster and a running stomach. I was sick that I had no blood [anaemic], and I had no strength. I used to complain a lot about my stomach and the pain that I had on my face. It was so painful that sometimes I would faint.”

Joyce continued working at the market during the period that Godfrey started with ART. She started with ART at the same time, but was at this time not feeling ill herself.

Godfrey explains that when he started with ART it was a very difficult for him. He feared going to the clinic because he was afraid of people knowing about his status. He says that taking ART every day and for the rest of his life was and remains something he finds very difficult: “At first I couldn’t bear the thing of taking the drugs every day”. In the beginning he says he had great difficulty remembering to take the drugs: “When I first started with the drugs, I used to forget most of the times”. Comparing the situation at home from before he became ill to how it was when he first started with ART he says that the “family was just okay and my wife used to love me and appreciate me, but when I started taking the drugs all that was gone. All she knew was to insult me in front of the children and other people.”
From the above case story we can see that there are many different ways that the news of being HIV positive can be received. It was already seen in previous case stories that people react differently to learning they or/and their spouse are HIV positive. The case story of Godfrey shows how he and his wife go through a very difficult time after learning that they are both HIV positive.

When Godfrey first becomes ill his wife, Joyce, shows concern and love towards him. He first tries to resolve the situation through traditional medicine but when this fails his wife takes him to the clinic. He and Joyce go for VCT at the clinic and are both found to be HIV positive. From this point forward things start to change between Godfrey and Joyce. She is very upset and angry with Godfrey. He explains that she stops sharing the bed with him, stops cooking for him, and that she started abusing him verbally.

Godfrey has also stopped working and explains that this also affected how his wife looked at him. He felt useless as he was unable to support his family. His wife too expresses this frustration towards him by telling him that he has become useless to her.

If we look carefully at the story we can see that Joyce blames Godfrey for the situation that they are in. She feels that he is “the one who has made her sick”. When we look at Godfrey’s account of how things the suggestion is made by him that he too feels responsible for his wife’s HIV status. When they are at the clinic he explains that he did not want to talk about certain things, and was unable to answer certain questions, because his wife was in the room. He explains how his wife verbally abused him and how this hurt him emotionally. However, accusations
from his side towards his wife are not present. While it hurt him deeply that his wife did not support him during this time he has not left her or accused her. Instead he is trying to rebuild his life and regain the trust, love, and respect his wife used to have for him. Finally at the end of the case story Godfrey says: “It is a very sad disease that has left many children orphaned and wives left as widowers – because of us men!”

At one point Godfrey feels so depressed that he considered to overdose himself so that he could die. He reports that he was scared to go to the clinic because he feared that people could find out that he is HIV positive. During this period Godfrey found support from outside the household: “people from the community helped me to see the other side of life, and made me more positive. I learnt about positive living.”

When first looking at Godfrey’s story one could easily focus on the negative sides. However, while Godfrey went through a very difficult time things seem to have improved and Godfrey has showed a lot of resilience and strength.

Now that Godfrey has recovered and has returned to work he feels that his wife is beginning to respect him again: “my wife has started respecting me a bit because I bring something home.” Regaining employment was not easy for Godfrey. He explains that by the time he was better his job had already been given to someone else. He didn’t give up though and begs his old boss. Through this proactive and perseverant attitude Godfrey manages to regain part of his previous employment situation.

The story suggests that Godfrey has tried to take back the control over his life and is making the best of it. He has returned to work and is supporting the family again. He is slowly rebuilding the relationship with his wife. His children are in school and the family situation is more or less “stable”. He has accepted his status and is using his own experiences to teach in the community.

Godfrey received support from the community when he was sick. Through this he learnt about positive living. He is now passing on this message to others by teaching “about HIV in the community”. In the last part of the case story we can also see how Godfrey now perceives HIV. While he admits that he wishes things were different he also takes responsibility.

Teaching in the community and regaining respect is a common theme. Many people report that they are open about their status and that they counsellors and are teaching about HIV in the community. Often people also link this to regaining respect.

“I am open about my status and there is no stigma. I am able to teach in the community.” (47 year old woman in Roma N’gombe)

“There is also no more stigma and I am now teaching people in the community about life and life choices and their life in the community.” (59 year old woman in Roma N’gombe)

“When I started with ART I had financial problems, I was chronically ill, and I faced a lot of stigma. Now I am a peer educator in my community. A lot of people consult me on various issues pertaining to their life. I am very well respected in the community through the work that I do to help others who are in need of counselling.” (51 year old woman)

“The stigma I first faced when I started ART has gone now, and I am able to teach people in the community which I never did before I became ill.” (59 year old woman in Roma N’gombe)

“I am a role model for people who still live in denial”. (44 year old man in Kalingalinga)
Supporting others and becoming a role model appears to be one of the ways in which people deal with their HIV status. The stigma that they faced before has made place for respect. Sharing stories and helping others who are also HIV positive is a way for people to deal with their own situation.

When people regain their health and physical appearance they are able to return to work. During the time that people are ill they often feel that they are a burden to others. Many people explain that by working they are able to provide for their family and that this gives them back their dignity. They feel that they are able to contribute to the family and are able to fulfil their duties.

In the following quote we can see how the various aspects of living positively come together.

“I am able to advice my friends on HIV.” (45 year old woman in Kalingalinga)

“Before I was stigmatised and I lost friends. But now people look up at me for advice and counselling on HIV and AIDS. I am a peer educator, a role model, and I am very respected in the community.” (50 year old woman in Kalingalinga)

“I used to be very stigmatised by people in the community, they used to give me suspicious looks. But I think that now more people are aware and are knowledgeable about HIV. Now there is more respect in the community. I am open about my status and share my story with others.” (37 year old woman from Roma N’gome)

Nevertheless my health has changed, such that I lost my weight and I have gained it back, also I remember that by that same time I had few friends but now all my friends are back. Finally, I am now counted in society because people are now respecting me.” (19 year old woman from Kalingalinga)

Change is there, I am no suffering from illness like I was when I started ART. The side effects are gone now and I am okay. My CD4 count has increased and it is now at 480. I have power and I am now able to work, I can even do hard work as I now have plenty of strength. There is also no more stigma (59 year old woman from Roma N’gome)

I am back to where I was before. I can do all the work for myself. I look better and people respect me now. (60 year old woman from Roma N’gome)

My life has been transformed I am back to where I was before. I am happy working and looking after my family. I do not go round looking for help. I am now a very capable woman. ART has improved my health and restored my dignity. (39 year old woman from Roma N’gome)

In the following quote we can see how the various aspects of living positively come together.

My health has improved very much. I do not suffer from illness the way I used to before I went on ART. I have changed my attitude towards the HIV infection due to having been attending workshops for people living positively. I am now empowered with better information; I have gained new friends, through my interactions with PLHIV. I am a respected person and people come to me for advice for ART and HIV Now I am back to before I got ill and doing even better because I have learnt a number of things, like public speaking during meetings, knitting for profit, and counselling clients. I am now able to live as a role model for those with self-stigma and therapeutic counselling for ART and TB patients. (56 year old woman from Roma N’gome)

The woman in the above quote has regained her health. She has managed to get into contact with other PLHIV and has made new friends. Through various workshops and meetings she has also broadened her knowledge
about HIV and ART. She now uses this information and her story as a means to assist others. Through assisting others her confidence has come back and she feels like she is contributing to society. When reflecting on her life she feels that she back to where she was before she was ill. Moreover, she feels that things are perhaps even better than they were prior to her illness. She has learnt new things from the meetings and workshops she attended. She now has access to tools and life skills that she can use to better her own livelihood but also to better the lives of others.

Returning to the body, mind, and sprit model we can see how these aspects are interlinked. In the above quote we can see that the woman has recovered her physical strength and is no longer suffering from illness (body). She has gained a positive attitude towards HIV (spirit) and has broadened her knowledge about HIV and ART (mind). Emotionally (spirit) she is now positive about life and has made new friends, in fact she even describes her life to be better than before she was ill. By recovering her physical health (body) she is now able to go out and teach in the community where she can contribute to society giving her a sense of importance (mind). The way she now perceives and understand HIV (mind) allow her to live a positive life (spirit).

**Economic hardship in abandonment – The impact of HIV on relationships and economic co-dependence**

Marriage’s, relationships, and families are put under a huge strain when someone falls ill. In some cases the news that someone is HIV positive can even mean the end of a marriage. The following case story discusses a story of a woman who is deserted by her husband when he hears she is HIV positive.

### Case story: Economic hardship in abandonment

Agnes is a 35 year old woman living in Roma N’gombe. She is married to Patrick who is 45 years old. Agnes has three children, one from a previous marriage and two with Patrick. The oldest child, Gift, is 15 years old. He attends school and is in grade seven. The other two children are still too young to attend school: Evans is five years old and Bright is three years old. Patrick works as a bricklayer and Agnes does some piecework (laundry) to supplement the household income. The monthly average household income is 450,000 Kwacha (~€69). The family rent a house in Roma N’gombe. The house has no access to electricity and for water they need to go to the public tap.

Before Agnes became ill she was married to another man than she is now. However, when she became ill her life turned upside down, this is her story. “Things started going wrong with my body in 2006. By then I was not working, but a full time house wife. I was visiting the clinic for various complaints almost every day and was given paracetemol until I was advised to take an HIV test. I tested HIV positive and disclosed my status to my mother when I went home. My mother became very hostile to me. She gave me eating utensils and told everybody in the household never to mix my things with the other utensils used by other members of the family. I was also ostracized and not allowed to talk to any of my siblings. By then I had one child and I was not working. When my husband heard the news he deserted me and he has never come back.”

Agnes experienced a very difficult time when she first started with ART. “Everything changed for the worse when I started feeling unwell before I started ART. My husband deserted me and my child. After he left me I first lived alone in a one room. But I was feeling unwell and there I had no one to care for me. So I had to go and live with my mother. But, it was very hard; I lived under very harsh conditions with her. When I started ART my body was weak, I had no appetite and could not manage to do much work. I experienced a lot of side effects from ART such as general body pain/weakness, cough, fever, and painful feet. I was afraid I was going to die and leave my child a destitute. My life was miserable. I experienced a lot of stigma and ostracism from my mother and siblings. During that time I only found solace at HBC. The caregivers took good care of me and helped me with food, medicines, second hand clothes and transport for going to hospitals for diagnostic tests. My friends from the HBC support group counseled me and reassured me that I was going to go through that phase and get better, provided I adhere to all doctors instructions.”
From the above case story we can see how Agnes went through a very difficult period when she became ill and discovered she was HIV positive. It also shows how vulnerable Agnes is. Agnes was economically dependent on her husband. When he left her, and this being compounded by the fact that her physical health was not allowing her to work, she was forced, to move to her mother’s house. Here she faced abuse and stigmatisation – but she had nowhere else to go.

During the time that Agnes is sick she finds little solace in her family. Instead she received help and support from outside – “During that time I only found solace at HBC”.

Agnes remarried after she recovered. Agnes explains that her health has improved, her strength has returned, and she no longer suffers from frequent illnesses. Agnes is able to assist her husband with the household income by doing some piecework. She says life has returned to normal.

When Agnes became ill her husband left her. Agnes is not the only respondent to mention that she was abandoned. In another case story (Living with HIV for more than one decade) the respondent, Beatrice, reported that she was abandoned twice. Beatrice explains that when her boyfriend discovers she is HIV positive he becomes scared that she and their child may pass away and that he will need to pay for the burial expenses.

“I was literally abandoned by my husband when I told him I was found HIV positive.” (49 year old woman from Roma N’gombe)

“I used to be a very beautiful woman and men desired me. But then I started to become ill. I never wanted to eat and I started to be slim and I developed a lot of black spots on my face. Then this is when the father of my child by the name of Joshua, a boy… well his father is married to another woman and he abandoned me saying I am not beautiful.” (29 year old woman from Kalingalinga)

“My first husband abandoned me a long time ago and has since died. My marriage was first okay. My husband did not show his true colours until I became ill. I have remarried, but all my seven children (4 boys and 3 girls) are from my first husband. I have no children with my current husband. I have to tell you my friend that I do not enjoy anything in my present marriage. My husband drinks a lot and he does not support me financially. I have problems in my marriage. I have a lot of emotional problems due to my husband’s cruel attitude. I cry most of the time. I wish I had somewhere to go.” (65 year old woman from Roma N’gombe)

“My problem started in 2010. I was married, had two children, so when I started feeling bad my wife left me for another man, she’s married till now, and she took both our children along with her.” (Man from Kalingalinga)

“I was HIV positive. When my husband heard this, he said “I cannot go to the clinic, this is your problem! I am not HIV positive! I cannot afford to buy food for you! I know how people like you eat too much food and too good food!” (47 year old woman from Roma N’gombe)

“When my husband heard that I had HIV he ran away and left me.” (27 year old woman from Kalingalinga)
The above quotes show how some of the respondents faced abandonment when their spouses discovered they were HIV positive or when they were very ill. When couples separate and they have children the children usually go with the mother. Culturally this is not surprising as Zambia is largely matrilineal and as such the children belong to the mother's side of the family.

To separate from your spouse or loved one is not an easy thing to do. Not only emotionally is this a difficult decision to make but it also brings other factors into play. These other factors can be both enabling or disabling when the decision is made to separate. Leaving a girlfriend or boyfriend is seen as easier than leaving behind your husband or wife. In one of the quotes above the respondent explains that her boyfriend left her because she was no longer desirable to him. Moreover, she explains he is married to another woman. His level of commitment to her is different than that to his wife. Now that she is sick he may be afraid that he may also be infected and that this could be passed on to his wife. If she finds out that her husband's girlfriend is sick this could potentially cause marital problems.

Often people are very dependent on one another in economic terms. There appears to be some evidence that economics does factor in when people decide to stay with or leave their partners. The economic dependence can mean that when a spouse decides to leave the other is economically crippled. When people are very ill this is even more so the case, after all they are often unable to work or care for themselves. In the case story of Agnes it can be seen that her husband’s decision to leave her left her economically crippled. She was no longer able to pay the rent and was forced to move to her mother. Some people explain that their spouse left, not directly because they are HIV positive, but because they were afraid of expected costs that were related to their HIV status. One reason that was mentioned earlier was related to the expected burial costs. In the above quotes another reason is mentioned, namely the expected rise in food consumption (both in quantity and quality).

At the same time there are people who would wish to separate from their spouses but are unable to do so for economic reasons. In the quote above we can see how one woman describes her situation and explains that her marriage is close to unbearable but that she cannot leave because she has nowhere to go. In a sense it is more difficult for women than for men to leave their spouse. Often women are partly or totally dependent on their husbands’ income, but moreover if they decide to leave they will need to take the children with them. Being solely responsible for the children and the extra costs of moving them will make moving extra difficult. It will most likely also limit the distance that women are able to move.
Separation is not easy and also not stigma free, as the following quote describes:

“My husband, he was very abusive, both verbally and physically. I stopped working as a maid, not because of illness but because of my husband’s behaviour which he extended to my work mates. Now that I am on ART and I have recovered everything has changed. I am now a very healthy person although I cannot find a job. My family situation has changed for the worst. I am separated from my third husband and life has become tough for me and my children. I am now the head of the household having separated from my husband. I have separated from my husband because I know I can live better on my own than in an abusive set up. Before I was ill I depended on my husband and hence I was abused. Although I worked I still thought marriage was very important for one to be respected. I am now a divorcee and people have a very low opinion of me.”

The respondent explains that she has left her husband because he used to abuse her. She also notes that it was impossible for her to leave him when she was ill as she was dependent on him. While the respondent does believe her life will be better without her husband she is also aware of the consequences. She now is the sole breadwinner for her children. She also notes that she has lost respect in the community and people have a low opinion of her because she has left her husband.

From the above and from earlier case stories it could be seen that marriages can be put under strain due to people discovering that they are HIV positive. In some cases people support and love each other from the beginning, other times it takes time to rebuild the relationship, and finally some relationships are ended. As was seen earlier there are also cases whereby the partner passes away. In many cases though people do find new partners and marry again. Stories which include second and third husbands and wives are not uncommon.

**A positive attitude – dealing with reality positively**

The last case story of this chapter describes a woman in her forties who is living alone, is not married, and has no children.

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**Case story: A positive attitude**

Joy is a 43 years old single woman who lives alone in Kalingalinga. The house she lives in is rented; the house has access to electricity and for water there is a tap outside the house. Joy works as a commercial sex worker and has an average monthly income of 1.5 million Kwacha (~€231).

This is Joy’s story of her illness and of how she learnt that she was HIV positive: “I started feeling bad in 2006, but, at first, I used to ignore it. Then I started having pains in my chest when I coughed. I also used to have frequent diarrhoea. Because of this I decided to buy some drugs from the drug store to ease the pain. Well it’s a shame to say this to someone I have never met before… but the fact is and the truth is that I usually go out in the night to look for money for food and rentals. I go to bars every day. Later, in the same year in December, that is when things became really bad for me, so much so that I wouldn’t even go for work in the night anymore. So my friends, who I used to stay at that time, they are the ones who took me to the clinic. At the clinic, that was when I was told to go for VCT and there the results came out positive. I started ARVs in January 2007 and my CD4 count was 88. At that time I used to have bad diarrhoea, it was so bad that when it came I would not even manage to rush to the toilet in time… I would mess just there. My relatives talked a lot, they told me that it was my own fault for me to be sick. They told me it was because I wasn’t married but I still had lots of man friends”.

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Joy never became bedridden and Joy explains that when she started with ART she was sickly but soon after she started with ART she recovered and was able to return to work: “before I used to have chest pains when I used to cough and diarrhoea a lot but when I started [with ART] all that went back to normal. I then went back to my old days working in the night in bars. But this time I started using condoms. Though I know that I am taking ARVs, but there is nothing I could do more than use condoms”.

Asking her if things are different now compared to when she first started taking ART, she replied: “A lot has changed! Like my eating habit, I eat a lot and my weight has gone up. Also my CD4 it is 600 now. I still work at night and I have a lot of customers, more than before even. My family has even stopped talking bad about me, I am still single and I feel fit. Anyway, I am managing to work, feed myself and I even eat a lot!” After a short pause she continues and says: “You know, those pains and the same diarrhoea I used to have before they have all stopped. I can tell you that the treatment is doing just fine. I have gained a lot of weight and I look so healthy that men at night can’t even notice a thing. I usually take my drugs at 7hr in the morning and at 19hrs in the evening and before I go out I make sure that I eat a very well balanced meal every day. I don’t forget my drugs because it is my life, you know what a lot has changed in my life since that time. I don’t even dream of getting married I am safe just by myself”.

When asking Joy if her life now is different than before she replies: “I know that the work that I do at night, the work that I used to do or still do, is exchanging money with sex. I can tell you that the more you sleep with men the more you have to have a lot of money. And the next day when you wake up you are happy. Because, well you know you will get what you want. Then well with problems, I don’t know. But even my family they feel that it’s okay. They say that I am a grown up so I can think for myself as long as I am happy with what I am doing. You know, when I first got sick they were pointing fingers. But now my family members stopped pointing fingers at me. ART has treated me so fine that I am fat and have gained weight a lot. Nowadays I have a lot of clients, I tell you! And I am not ashamed, because that is how it is and how I make my living. I am too strong and I make sure I use condoms”.

From the above case story we can see that Joy was working as a commercial sex worker before she became ill and after she recovers returns to the same work. Joy was taken to the clinic by her friends because she was not feeling well. This is where she discovered she was HIV positive. Joy does not mention difficulties or disbelief regarding her status. This may be because she is aware of the risks that are involved in the work that she does. In fact, today she takes precautions for further infection by using condoms.

Joy explains that while she realises she is HIV positive there is little she can do other than use condoms. Changing occupation is not an option for Joy – “this is how it is and how I make my living”. Joy is dependent on herself to make a living and look after herself. She explains that it is through her work that she is able to raise enough money to look after herself well.

When joy was visibly ill she suffered some stigma from her family. Joy explains that her family blamed her for being sick – “My relatives talked a lot, they told me that it was my own fault for me being sick. They told me it was because I wasn’t married but I still had lots of man friends.” When joy recovered her strength and was able to look after herself the stigma however disappears. Joy explains that her family has “stopped talking bad about me” and that “they say that I am a grown up so I can think for myself as long as I am happy with what I am doing”. It appears that the stigma she suffered only lasted during the period that she was ill and dependent on others for assistance – “you know, when I first got sick they were pointing fingers. But now my family members have stopped pointing fingers at me”. This is not an uncommon finding, earlier it was seen that when people’s physical health returns the stigma also for a large part appears to stop. Joy is blamed by her family for getting HIV, they feel that her choice of profession is what has led to her becoming HIV positive. However, once Joy recovers and
returns to work the stigmatisation from her family stops. The stigmatisation stops despite the fact that Joy continues with the same work that they feel caused her HIV infection. While it is unclear if Joy also supports the family financially there does appear to be a connection between stigma and economics. When people do not need assistance and can look after themselves much of the stigma disappears.

After Joy recovered she was able to return to work. ART she says “has treated me so fine that I am fat and have gained weight a lot.” The illnesses she was suffering from have all disappeared and her strength has come back. She is now so healthy that she says “I can tell you that the treatment is doing just fine. I have gained a lot of weight and I look so healthy that men at night can’t even notice a thing.”

Joy shows a lot of strength throughout her story. She is happy with her life and looks after herself well. Joy explains that she eats well and makes sure that she takes her ARVs everyday – “I make sure that I eat a very well balanced meal every day. I don’t forget my drugs because it is my life.” Joy appears to be happy with her life and explains that she is single and fit and that she now no longer dreams “of getting married, I am safe just by myself.” This statement is a testimony of Joy her strength and confidence in herself. This confidence is also projected when she talks about her work – “I am not ashamed, because that is how it is and how I make my living. I am too strong and I make sure I use condoms.”

Joy recovered her physical health (body) and this enabled her to return to work and look after herself. By becoming independent once again the stigma she was suffering from has disappeared. Joy is now again a strong woman and positive about her life (spirit). While joy is aware that she is HIV positive and could potentially infect her clients she is aware that condoms can protect both her and her clients. She is also aware that she is dependent on her work for her income (mind). She is happy being single and looking after herself, she does not need to get married to be happy (mind/spirit). Finally, Joy realises that by looking after herself well she will stay healthy.

8.2.3. Conclusion
In this section a number of themes were discussed. In order to do this a number of case stories were presented and for each a specific aspect, or aspects, was highlighted. Where possible, quotes from other respondents were also discussed. Finally, where possible, the body, mind, and spirit model was used.

This section served to answer the following research question:

- How do HIV positive individuals, and their households, receiving ART understand and experience their current lives, and how does this compare to their life before HIV and when they first started with ART?

Research findings
In this research three periods of life were focussed on: before illness, start ART, and the current (after illness) situation. While these three periods do exist this does not mean people experience these in the same way. Not only do the stories differ they are also understood and experienced differently by people. People’s mind, body, and spirit are not affected in a uniform way. Some respondents became very ill and their physical health was severely affected while others suffered only from minor side effects (body). The beliefs and attitudes (mind) regarding HIV was seen to differ between individuals: while some people accepted their status and started with ART with relative ease others at first refused treatment and feared that the drugs would not improve their health. Finally the emotional impact on people was experienced differently: some people felt rejected and had no hope for recovery while others took a proactive stance and felt hopeful that the drugs would improve their health.
Households too are not uniform and are not affected in a uniform way. When both people in a couple are found to be HIV positive the outcome for the two individuals can be very different. In the first case study we looked at a situation whereby a woman lost her husband due to HIV and she had now become the head of the household and sole provider for her children.

Early discovery can impact the trajectory people go through in a positive way. When people discover that they are HIV positive before they become very ill and start ART on time, this can increase their chances of not becoming ill. By not going through a period of severe illness not only impacts the individuals’ health but also the household as a whole. People do not need to stop working and potentially lose their job. As such the household income is not affected and other household members do not need to supplement this income loss or spend time and resources to care for the sick household member.

Early discovery can also impact the fate of children positively. PMCT can then be implemented which in turn increasing the chances that a child is born HIV negatively enormously. But also the well-being of other children in the household can be increased. ART has the potential to protect children from becoming orphans. Additionally with early discovery and early initiation of ART some economic hardship may be averted. Children may then not need to be taken out of school or face the difficulties of needing to take care of their sick household member.

Children are also one of the motivating factors for people to start with ART. People are often afraid of leaving their children behind: people are worried about their children’s fate and about who will look after them in the event that they pass away. Some people said that they accepted their status and started with ART because they wanted to become better in order for them to look after their children.

Acceptance is a difficult thing for people, both in coming to terms with their HIV positive status as well as in accepting to start with ART. Not everyone accepts immediately, and many people go through a stage of denial. As such, even when early discovery is there not everyone is able to take advantage of it. On the long run this can have major impacts on individuals and households. When people are unable to accept the situation and go into denial this eventually impacts their physical health. Some people reported that they only started with ART when they became hospitalised. Starting with ART at such a late stage increases a person’s morbidity and mortality. As such delaying the start of ART not only increases the chances of a person first becoming very sick it can also lead to them dying. Additionally, delayed start of ART is also linked to a lower restoration of the immune system and as such a lower quality of physical health. Illness and death not only impacts the individual but also the household as a whole.

ART has been available for less than a decade and fresh in the back of peoples mind are the devastating outcomes of HIV before ART. For many people the fear of death paired with HIV is still very present. Many people remain afraid that PLHIV will die. This fear of death is often paired with stigma whereby people are stigmatised and told that they will die soon. When people are stigmatised and feel rejected by their friends and family they after lose all hope and fear that they will die soon.

There are however also changes in the attitude. More and more people are beginning to see the benefits of ART and realising that the reality of HIV is changing. There are stories of people who explain that their relatives encouraged them to get treatment and support and stimulate them to continue with their medication. People can also be motivated to start with ART in order to avoid becoming ill and be further stigmatised because of this. Knowledge and believing that ART can improve your physical health (mind) as well as a positive attitude and mental strength to act (spirit) can lead to early initiation of ART and this in turn can lead to improved physical health (body).

Support and care from family can be very important in the recovery and acceptance process that people go through. When people are supported, loved, and cared for when they are sick and when they discover their HIV
status this can make the process of acceptance and recovery far easier. By not being rejected people may also become more open about their HIV status. Through being open people also find support outside of the household and avoid becoming isolated.

Support and love does not always come from people’s direct environment. Some people go through many difficulties with their families and even feel rejected and stigmatised by them. In some cases this rejection and stigmatisation starts becoming less when they start to recover their physical health and start working again. When people are stigmatised in their household then support from elsewhere can be very important. The community that people are living in can play a big role in the recovery process of people and can become particularly important when this support is lacking in the direct environment.

When people regain their health and physical appearance they are able to return to work. During the time that people are ill they often feel that they are a burden to others. Many people explain that by working they are able to provide income for their family and that this gives them back their dignity. They feel that they are able to contribute to the family and are able to fulfil their duties.

Many people reported that, now that they had recovered, they were open about the status and felt they played an important role in their community. People reported that they were counsellors, peer educators, and living testimonies of the effects of ART. Supporting others and becoming a role model appears to be one of the ways in which people deal with their HIV status. The stigma that they faced before has made place for respect. Sharing stories and helping others who are also HIV positive is a way for people to deal with their own situation.

Marriages can be put under strain due to people discovering that they are HIV positive. In some cases people support and love each other from the beginning, other times it takes time to rebuild the relationship, and finally some relationships are ended. Some of the respondents faced abandonment when their spouses discovered they were HIV positive or when they were very ill. Often people are very dependent on one another in economic terms. There appears to be some evidence that economics does factor in when people decide to stay with or leave their partners. The economic dependence can mean that when a spouse decides to leave the other is economically crippled. When people are very ill this is even more so the case, after all they are often unable to work or care for themselves. When people are abandoned they find themselves in need from support from elsewhere. This situation however is not always ideal and can go paired with a lot of stigma.

Discussion
Throughout the stories it can be seen that a positive attitude is very important. People who are resilient and have a positive outlook on life not only seem to enjoy their life more but also are more successful in the choices they make. This positive outlook is partly connected to the support and love that people do or do not receive. When people persevere and get better things do improve and stigma reduces.

Returning to the body, mind, and spirit model we can see how these aspects are interlinked. When people recover their physical health (body), have faith in ART and belief that they can continue with their life (mind), and have a positive attitude and are hopeful about the future (spirit) then their situation can be viewed as relatively good. What is also apparent is that all three aspects need to be present because they are highly interlinked. When people are for example physically ill then they are unable to work and (self-)stigma may return which again affects their mental well-being (spirit). Not being able to accept your HIV status (mind) can lead to a deterioration of a person’s physical well-being (body) as well as affect their mental well-being (spirit).

The surroundings, both in terms of the direct family and household as well as the community, plays an important role in the way people experience and understand their life trajectories. When people are for example faced with an HIV positive status which they cannot understand because to their knowledge they have always been faithful then acceptance may be harder. If people are then not supported and instead stigmatised the person may feel
even more emotionally strained and rejected. This can lead to denial and starting with ART at a late stage. Instead if people are less troubled about the how but instead worry about the future and find support and love in their environment they may be encouraged to start with ART earlier.

Finally, stigma appears to be rife when people are most ill. If people become ill they are no longer productive and in a sense they perceive themselves as a burden to their families. If people test early and start with ART before their health has been affected then in many cases people’s health will be far less affected. If people are then able to continue working they may also experience less stigmatisation. What is not lost, for example a job, physical health, or one’s self esteem, also does not need to be recovered later.

8.3 Implications for theory

8.3.1 Introduction
In the previous section it could be seen how individuals can experience and understand their lives in different ways. It was also seen that the trajectories and the way people experience and understand their lives can both impact and be impacted by the people in their surroundings. Clearly people are embedded in their surroundings.

In earlier chapters the socio-economic situation of PLHIV and their households was discussed. Conclusions were drawn about how things change over time. Factors that may influence the trajectory were discussed. And finally, in the previous section, the individual understanding and experience was introduced. In this section the different conclusions will be discussed and brought together. By focusing on the interconnectedness of the model a more full understanding of the well-being of PLHIV on ART can be gained. The following research question will be answered in this section:

- How do the different conclusions relate to each other and what does this say about the well-being of PLHIV on ART, and their households?

8.3.2 Combining conclusions
In this section a closer look will be taken at how the theoretical framework fits in with the conclusions of this research. By taking a closer look at two PLHIV and comparing their trajectories an examination of how these trajectories can be influenced can be shown. These individual trajectories can then be placed into the theoretical framework. This will allow for a closer inspection of how the various parts of the theoretical framework fit together and how these can influence the trajectory of individuals. Following this a broader discussion will follow on the theoretical framework and the conclusions from this research.
Comparing two trajectories
In the following diagram two trajectories have been compared.

Figure 8.1: Comparing two trajectories over time

In the above two trajectories it can be seen that both the individuals in question are working prior to their illness. Mary is working as a security guard and John as a gardener. Mary currently still works as a security guard, and was able to continue working when she started with ART. John however lost his employment when he became ill and while today feels able to work has not managed to find permanent employment.
From the above stories it can be seen that Mary went for VCT prior to her becoming ill and that when she started to lose her appetite, and as a result of this weight, she went back to the clinic and started ART. John went to the clinic when he started feeling ill, however when he discovered he was HIV positive he fell into a period of depression and denial. John explains that he went to different clinics because he did not believe the results of the HIV test. Although the results of the HIV test in the various clinics all came out positive he did not accept his status and refused to start with ART. John only starts with ART after his health has decreased tremendously and he is hospitalised.

When John was very ill his wife left him and he had to return to his parental home for care and support. He was completely dependent on his family and went through a very difficult time. When John discovered his HIV status his physical health was fairly close to that of Mary when she started with ART. Perhaps John would have been able to continue working and supporting his family if he had started with ART immediately after discovering he was HIV positive. However, because John was unable to accept his HIV status immediately he delayed treatment, lost his job, and became dependent for care and support from others.

What has been lost is hard to recover, perhaps even more so for people living in Roma N’gommbe. Earlier it was seen that people in Roma N’gommbe often face greater difficulties to find employment than people in Kalingalinga. John was working as a gardener prior to his illness and while able to work he has not managed to find permanent employment yet. He is dependent on any piecework he finds. Mary never lost her employment and as such has also not needed to recover this.

When John started with ART he was very ill and had a CD4 count of 114. Mary instead, while having lost some weight and strength, was not very ill and started with ART when her CD4 count was 320. John’s self-reported health status today is “very good” which would indicate that he has recovered well physically. However Mary reports that her health is “Excellent”. Mary her CD4 count today is also higher than that of John.

When asking them to reflect on their lives today Mary says: As for now everything is ok because I have gained back whatever I lost. Mary her life today is much the same as it was prior to her discovering her HIV status or starting with ART. This is different for John who lost his job, moved back to his parents, lost his wife for a period of time, and feels that life now has a lot of restrictions. Mary never lost her job, her health never deteriorated severely, and, having lost her husband many years prior to her discovering she was HIV positive, lives in the same household as she did prior to her illness. Mary lost less than John and as such also had less to recover.

From the above we can see how Mary her pro-active attitude has enabled her to mitigate the effects of her HIV positive status. It can also be seen that the phase of denial that John went through has caused for a very different outcome.

Both these trajectories can be placed into the theoretical framework. For both trajectories a closer look will be taken at the livelihood pentagon resources, the Ecological Systems Theory (EST), and the body, mind, and spirit model (BMS). In addition for all three models the changes over time (Chronosystem) will be looked at. The two trajectories will first be discussed separately and then compared.

Trajectory 1: Mary
The first trajectory that will be looked at will be Trajectory 1: Mary. In order to place Mary her trajectory into the theoretical model first the individual will be focused on and then the microsystem. In figure 8.2 on the next page this can be seen.
Figure 8.2: Operationalisation of Trajectory 1: Mary
In the above operationalisation two of the EST levels are explored: namely the individual and the microsystem level. Within the individual level both the livelihood pentagon and the BMS model have been placed and examined. Within the Microsystem level the livelihood pentagon has been placed. The various microsystems of the individual were explored and discussed in relation to the potential resources that they may offer. Additionally, the various resources that are available within the household are explored.

Zooming in on the BMS model it can be seen that Mary her physical health (body) is good today, that she has faith in ART, has accepted her HIV status, and is has embraced “positive living” (mind), and that she has a very positive attitude and is positive about the future (spirit). Placing the factor time (Chronosystem) into the model allows for an examination of the BMS model over time. It can be seen that Mary had a very positive attitude (spirit) throughout her trajectory. In addition, Mary went for testing prior to her becoming ill and was never surprised of concerned that she tested HIV positive. She has been aware of HIV, the way it is transmitted, that she can take ART and that ART can allow her to continue her life and stop her from becoming ill throughout the process (mind). The main change that occurred over time in the BMS model is related to Mary her physical health (body). Mary started to lose her appetite and as a result of this started losing weight and became weak. The loss of appetite made her go back to the clinic where she then started with ART. Mary her physical health (body) was affected, however, Mary never suffered from severe side effects, frequent periods of illness, was never bedridden, and was always able to continue working.

Following this a closer look can be taken at the livelihoods pentagon. This is closely related to the BMS model. When looking at Mary her physical health (body) it is clear that this is related to her human resources. If her physical health deteriorates this can impact her human resources and if Mary is unable to work this will then impact the other resources. Looking at figure 8.2 it can be seen that Mary today is physically able to work and is working as a security guard. She has no natural resources, which is common for urban areas where physical resources play a far more important role. She owns the house she is living in and has quite a range of assets, including a bed, a mobile phone, and a TV for each person in the household, some furniture, a fridge, and a stove. Mary is the sole breadwinner in the household; she is formally employed as a guard and has a stable income (financial resources). Mary lives alone with her daughter but also has contacts outside the household, these include: friends, Kalingalinga HBC, neighbours. Looking at Mary her resources over time we can see that mostly the situation has remained the same over time. At the start of ART she joins the Kalingalinga HBC, making this part of her social resources. Her human resources are compromised due to her physical health (body) having deteriorated. However, while Mary is feeling less weak and less able to work she is able to continue with her employment and none of the other resources are affected.

Mary is the head of the household and as such many of the resources in her household belong to her. This is often not the case and moreover it is often unclear who the specific owner of a certain resource may be – this is particularly the case for physical resources. Household assets are often seen as belonging to the household or to the head of the household.

When looking at the setting in which Mary lives we can see that the microsystems that surround her include: her family (household), friends, neighbours, Kalingalinga HBC, Church community, and her workplace. These are similar to the social resources that were mentioned earlier. Social resources of an individual are often also the microsystems that surround an individual. Mary her human resources include her household, friends, neighbours, and Kalingalinga HBC. These are all mentioned by Mary as people she can turn to in case she needs assistance of advice. The Kalingalinga HBC can be seen as a social resource for Mary, it however also plays a part in other resources. It is mentioned by Mary as a place where she may turn to if she needs assistance with household chores, but also a place she can go to for information and knowledge regarding her health but also for advice on livelihood strategies (human resources). If she is in need she may also be able to get financial support from here.
Finally it is also potentially a source for physical resources – she may be able to follow courses here and get information.

Mary never suffered through any period of severe illness and never needed any assistance. As such, the microsystems in her environment also were never placed under stress. The only microsystems that have changed over time are the Kalingalinga HBC, because Mary only joined this HBC when she started with ART, and her church community. When Mary started with ART she had stopped attending church, she explains that she did not have enough energy to attend church. While she has now recovered she has not returned to church, although she says that she intends to do so soon. Mary also never suffered any stigma and was not abandoned by any of her relatives of friends. As such, here too little has changed over time.

Zooming in on the Household as a microsystem it can be seen that Mary, as the head of the household of a small family, is herself the largest asset to the household resources. Her daughter has recently turned eighteen and has completed secondary school and is now attending higher education. While the daughter is physically able to work, Mary has chosen instead to continue investing in her daughters’ education. In the future this investment may prove to enhance the households’ resource pool.

Next the second trajectory that was discussed will be explored within the theoretical framework. Having compared the two stories previously it was seen that the choices made by Mary and John differ. The outcomes of both trajectories differ too.

**Trajectory 2: John**

In the following figure the second trajectory will be discussed on the individual level. First the BMS model will be discussed and then the livelihoods resources will be looked at.

<table>
<thead>
<tr>
<th>INDIVIDUAL</th>
<th>Trajectory 2: John</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Body</td>
</tr>
<tr>
<td>Current situation</td>
<td>CD4 count: 538. Self perceived health: very good. Able to work and strength has returned. Feels restricted in what he is able to do.</td>
</tr>
<tr>
<td>Start ART</td>
<td>Bedridden, hospitalised, suffering from TB. Low CD4 count of 114. Very ill and very weak.</td>
</tr>
<tr>
<td>Before illness</td>
<td>Healthy and strong</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Human resources</th>
<th>Natural Resources</th>
<th>Physical Resources</th>
<th>Financial Resources</th>
<th>Social Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current situation</td>
<td>Physically able to work. Unemployed. Does piecework wherever this is available. Did not complete primary school.</td>
<td>None.</td>
<td>Lives in parental home (see microsystem household).</td>
<td>Occasional income through piecework. Dependent on other household members (see microsystem household).</td>
</tr>
<tr>
<td>Start ART</td>
<td>Physical health compromised – bedridden and unable to work. Same as now.</td>
<td>None.</td>
<td>Same as now.</td>
<td>Same as now.</td>
</tr>
<tr>
<td>Before illness</td>
<td>Physically able to work. Employed as gardener. Education same as now.</td>
<td>None.</td>
<td>Lived in a rented house with his wife. Assets moved to parental home.</td>
<td>Secure income source informal employment as a gardener for a wealthy family n Kalundu.</td>
</tr>
</tbody>
</table>

*Figure 8.3: Operationalisation of Trajectory 2: John – Part 1: Individual level*
In the above figure it can be seen that John’s physical health today is good and he is able to work (body). John has accepted his HIV positive status and is now able to teach in the community (mind). He has a positive attitude and feels that things will continue to improve and that he will soon find a job (spirit). John however has not always been positive about his HIV status (mind), his physical health has only recently become good again (body), and not long ago he was depressed and had no hope that he would ever recover (spirit). Looking at the changes that John has gone through over time (Chronosystem) within the BMS model can provide an insight into how John experienced the changes he has been through.

When John discovered he was HIV positive he did not believe that it was possible that he was HIV positive. John went to various other clinics and even after they confirmed that he was HIV positive he was unable to accept his HIV positive status (mind). By the time that John starts with ART his physical health has been severely affected (body). He is bedridden, has been hospitalised, he is very weak, and his CD4 count has dropped to 114. John is depressed and has no hope that he will ever recover (spirit). He feels stigmatised and has been abandoned by his wife. Before John became ill he was healthy and strong (body). He was positive and not worried about the future (spirit), and he did not worry or think that he could ever be HIV positive (mind).

Over time things have changed for John. He went from being physically healthy and strong, to bedridden and weak, and is now recovering his physical health and feeling stronger (body). Before John became ill he never imagined he could be (come) HIV positive (mind). When he tested HIV positive he could not accept his HIV positive status, John became depressed and denied his status (mind). Now that John has recovered he has accepted his status and is able to teach about it in his community (mind). Finally, John enjoyed life and was positive and hopeful for the future before he became ill (spirit). This changed dramatically when he became ill, he became depressed and had no hope for the future or that he would ever recover (spirit). Now that he has recovered he is again positive and hopeful for the future (spirit).

The changes John went through are very different from the ones Mary went through. Armed with more knowledge and faith in the future Mary managed to avoid many of the negative aspects that John has had to go through. Had John immediately started with ART his physical health (body) may not have deteriorated as much. Similarly he may not have felt so hopeless and depressed (spirit).

A closer look at the resources pentagon again shows how the BMS model is related closely to the resources available and how they are impacted. Before John became ill he was healthy and able to work (Human resources). John and his wife lived together in a rented house (body, physical resources) and through John’s job as a gardener they had a stable source of income (financial resources). When John became ill his health deteriorated and his ability to work first diminished and later disappeared completely (human resources), this had an impact on the households’ income (financial resources) which in turn affected their living situation. When John was unable to work (human resources) and support his family (financial resources), his wife left him (social resource) and he was unable to pay for the rent of their home (physical resources). John moved back to his parental home where he was looked after by his family. At this time his physical resources, financial resources, and social resources changed. These changes are still there today: John still lives in his parents’ home (physical resources), and is largely dependent on his parents as he has no stable income (financial resources). His social resources have improved since his illness. John again feels respected and next to his family and the Roma N’gombe HBC now also spends time with friends, his neighbours, and the community at large. His wife has also come back to him.

Having looked at the individual level the microsystem level can now be discussed. First the different microsystems that exist will be discussed.
From the above it can be seen that John has had and continues to have a number of microsystems around him. These however diminished severely when John was ill. He was abandoned by his wife and was forced to look for support elsewhere: John found the support he needed in his parental home. During the period John was ill he was supported fully by his parents. Next to his parents he received some support from the Roma N’gombe HBC. Before John became ill and currently there are more microsystems surrounding John. Currently Johns’ microsystems include: his family (household), friends, neighbours, community, and the Roma N’gombe HBC. This is similar to before John became ill, only that he was not part of the Roma N’gombe HBC and that his household was different. Both John’s family (household) and the Roma N’gombe HBC can be seen as Human, Physical, Financial, and Social Resources. John his human and social resources include the household, friends, neighbours, and Roma N’gombe HBC. These are all mentioned by John as people he can turn to in case he needs assistance or advice.

Taking a closer look at the household as a microsystem provides the following:

Looking at the household as a microsystem it can be seen that many things have changed over time. John’s household first consisted of him and his wife. When John became ill his wife left him and he moved back to his parental home. John still lives with his parents today, and as he started recovering his wife returned to him and is now living with him in his parents’ home. His household as such grew from 2 healthy and able to work adults to 7 healthy and able to work adults (human resources). When John moved to his parents’ home his physical resources changed. Before he lived in a rented house (with access to electricity) together with his wife now he lives in his parents’ house (with no access to electricity). John previously was employed as a gardener (financial resources) but when he became ill he lost this job and up to today is largely dependent financially on other family members.
From the above two trajectories it can be seen how trajectories can be very different and that these differences can be seen on the various levels of the theoretical framework. It also shows how the different parts of the theoretical framework influence each other and are interrelated. By looking at all the parts a better understanding can be gained about the well-being of PLHIV and their families. The above analysis however omits the larger part of the EST model. In the following section a broader discussion will follow with regards to the theoretical framework in combination with the various conclusions of this research.

8.3.3 Theoretical conclusion
The Microsystem has been conceptualised as ‘the settings in which a person lives’ and comprises of all everyday activities and experiences of an individual. As such, this can be a manifold of spaces, such as: the household, the (parental) home, the family, the school, the workplace, the community, etc. It is important to acknowledge that microsystems are not distinct and separate islands but instead are an interwoven dynamic of microsystems: the mesosystem. It comes as no surprise that most of the evidence and most of the personal stories are embedded within these microsystems. Additionally, they do not often relate to other systems such as the exosystem or macrosystem. Within these microsystems the personal body is an important factor; in here the personal body is not limited only to the physical health (Body) of a person but also to the person’s Mind and Spirit. The evidence gathered for this research suggests that the BMS Model should be placed within the individual scale level as seen in the EST. This individual level and the BMS model influences and is influenced by the microsystem(s), and, as such also, the mesosystem.

This research does not suggest that the exosystem and macrosystem are not important. However, it is suggested that for a large part they do not form the daily reality of the participants. The exosystem and macrosystem play a role, not in the daily realities of individuals but play a role in the big narrative. An example of this can be found in terms of culturally based gender roles (macrosystem) or within the influence of the national health care system that includes specific ART guidelines and standard HIV testing for pregnant women (exosystem). These influences will be discussed later, however, for now, the focus will be on the level of the everyday life experiences: the individual, the microsystems, and the mesosystem.

The purpose of this theoretical exercise is to merge the EST with BSM into the livelihood pentagon framework. This means focussing on the individual and his/her lived experience and their direct (social) environment. To explore the time dimensions the chronosystem of the EST is the guiding time principle as it emphasises the dynamics and changes over time. As this research looks to implications over time the chronosystem is of vital importance. The exercise below aims to provide an insight into the links between the three models.

The first and foremost direct impact of HIV is on the physical health, which is of course no surprise. As the HIV infection progresses people’s physical health becomes more and more affected. Common symptoms mentioned by people include: diarrhoea, weight loss, lack of appetite, general weakening of the body, etc. Depending on the stage of the HIV infection people start with ART their physical health can be more or less affected. There appears to be mounting evidence that men accessing ART disproportionally less than women. Additionally, on average men start with ART in a more advanced stage of HIV infection, have lower survival rates than women, are more likely to interrupt treatment, and are more frequently lost to follow up (LTFU) to ART. Starting late with ART can have a huge impact on the possible results of treatment: Lower CD4 counts at start of ART have been identified to lead to higher mortality and LTFU amongst patients. Moreover, there is now mounting evidence that there are long term negative effects of starting with ART at a late stage: people who start with ART with lower CD4 counts also appear to have lower CD4 counts 7 years after the initial start of ART, compared to people with higher CD4 counts at start of ART.
The Zambian Health Care System (an exosystem) provides ART to PLHIV. A set of guidelines is followed to determine when people should start with treatment. These guidelines are largely based on the old WHO advised guidelines\textsuperscript{102}. Within the health care system there are a number of entry points for people to access ART. Some of these entry points can lead to early detection of HIV infection: in principle all pregnant women in Zambia who go for antenatal care are tested for HIV (only if a woman specifically “opts-out” and makes clear that she does not want a HIV test is she not tested for HIV). While this exosystem is not directly part of people’s lives and experiences, it can have a huge impact on their trajectory. When people are tested in an early stage of infection they may be able to start with ART early, thus avoiding that their physical health (body) is affected negatively. A person his/her body and health is a human resource. When this is affected it can also affect other resources and there are multiple possible consequences for PLHIV and their household.

When a person’s health diminishes his/her ability to work also decreases. When this happens the human resources of the entire household (as microsystem), and not only of the infected individual, is affected. Once the human resources are affected this may also have consequences for other resources. The livelihoods pentagon is an interwoven entity, and resources are linked to one another: when one resource is affected this can affect the other resources. When a person becomes sick for a longer period of time, this may also have consequences for someone’s potential to work and generate income. Multiple stories were collected in which the breadwinner or head of the family loses his/her job due to illness. The loss of this income affects the household negatively, and when this was the main source of income for the household there can be dramatic consequences. The loss of human resources leads to a loss of financial resources and may result in people putting into place certain coping strategies, these include: taking children out of school, diversifying income sources, and changing the households food income to less costly products, selling of assets.

When people start with ART at a stage before they have become ill and are unable to work some of these consequences may be avoided: ART mitigating the negative consequences of HIV. The current Zambian guidelines for ART (part of the exosystem) recommend that people with a CD4 count below 350 should initiate with ART. The new WHO guidelines have moved this to a CD4 count threshold of 500. In some instances this means that when people are first tested they are not immediately started on treatment and will need to monitor their CD4 count. Similarly people may only go for VCT when they are already experiencing losses in their physical health. This delay may cause peoples health to first diminish before they are started on treatment. A decrease in peoples’ physical health (human resource) can lead to a decrease in their ability to work and generate an income (financial resources). When financial resources are lost people may increasingly feel pressured to sell off assets (physical resources). Following this people may also need to ask for assistance which may put social relations under pressure (social resources). As discussed before, that which is not lost also does not need to be recovered: when someone starts late with ART the recovery process also takes a long time and moreover there is no guarantee that someone comes back to the ‘before illness’ phase even if they have been on ART for years. Here it becomes clear how important the chronosystem is when examining how ART can influence the well-being of PLHIV and their households.

This research would suggest that there is a Janus-faced relation between HIV discovery and treatment on the one side, and social resources on the other side. Especially the stories from the first part of this chapter reveal the complexities surrounding social resources. Some stories show that a positive HIV test and intake of ART can lead to stigmatisation of PLHIV. This stigmatisation is not limited to the household, but also to relatives, and the community. A somewhat provocative preliminary conclusion is that the stigmatisation is a result of the inability of PLHIV to work and contribute to production processes and income generating activities. PLHIV, especially men, seem to feel discriminated or useless because of their inability to financially contribute to their household. Many

\textsuperscript{102} The WHO recently published new guidelines. Previous decisions by the Zambian government suggest that it is likely that Zambia will implement the new advised guidelines; however, this will take time.
stories include people mentioning that they suffered from self-stigma. For men it is very important that they are able to work – through working they can show off their masculinity. For women it is of vital importance that they are able to care for their families. When people’s physical health decreases and they are no longer able to fulfill their roles people start perceiving themselves as a burden (mind) which may finally also cause them to feel stigmatised, depressed, and hopeless (spirit).

Other explanations of stigmatisation can be found within the lack of knowledge about HIV. Stories whereby people are given their own utensils and plates for food, as to avoid contamination sadly still exist. A third explanation of stigmatisation, perhaps more relevant within the household is a reaction towards the one who introduced HIV in the household. For instance, a man with a loose sex-life can be stigmatised for being infected and spreading HIV within the family. A fourth explanation can be derived from the chronosystem, namely the collective memory of HIV/AIDS which caused a lot of illness and death in Zambia in the past. Until 2004, ART was not freely available for the PLHIV and HIV was seen and experienced as a death sentence. A new collective memory is also being created – one of hope and life on ART. However, there are also stories of people dying on ART and this too can lead to fear of death and discrimination.

Social resources can instead also play a very positive and important role. When people accept HIV, ART, and a life with HIV they do this within their microsystems, and the social relations that are part of this. It is not a rarity that a relative or a friend encourages someone to test for HIV, take their medication, or even to take care of someone who is ill or suffering from side effects. Multiple stories of people who became bedridden and were taken care of by friends, parents, or partners are included in this research. The community and HBC programmes cannot be neglected as projects: social supports group are proven valuable for the mental well-being of the PLHIV. Results from this research would suggest that the higher degree of mental well-being in Roma N’gombe compared to Kalingalinga may be a result of the presence of a more successful HBC programme in Roma N’gome than Kalingalinga – a suggestion that is supported by several interviews. Interesting is also that PLHIV can strengthen their social resources by becoming active in the community as, for instance, an educator on (living with) HIV. Teaching in the community provides people with a means to come to terms with their status (mind/spirit), regain respect in the community, feel useful, and strengthen their social resources.

The above elaboration shows that HIV not only affects HIV positive individuals themselves, but also their microsystems. The most direct influence will be on the household and family, but also other microsystems are affected: neighbours and friends may be asked for assistance but also communities lose their, often most, productive members. These effects are most present when an individual indeed becomes ill. While ART is now mitigating some of these effects and has the potential to increasingly do so the effects of the HIV epidemic can still be seen. Demographically speaking the effects of the HIV epidemic can be seen, these effects partly stem from an era prior to ART. Looking at the population pyramid found in this study, but also in other studies and have been predicted as a result of the HIV epidemic, show gaps in specific age groups. Additionally, there is also mounting evidence that men are missing on all fronts. With fewer men in ART roll-out programmes, more men starting late, more men stopping with ART, and ultimately more men dying, there are also fewer men available in society, their communities, and their families. This is not only directly affecting the health of these individuals but has a number of other consequences. Women are already in a vulnerable position, often they too are HIV positive and on ART, if their husbands fall ill the burden of care will fall on them, additionally if their husbands die they will now also take over the full responsibility as head of the household. As such, fewer men accessing ART is affecting not only the health of individuals but is also affecting the welfare and well-being of households, communities, and ultimately entire societies.

Clearly HIV affects not only the human resources, financial resources, physical resources, and social resources of individuals and their households. The consequences are felt more widely, after all individuals act and influence a wide range of microsystems, such as their household, workplace, community, church, etc. Within this it should
not be forgotten than individuals are different, have different priorities, have different options, and react differently. Here we return to the Body, Mind, Spirit model which emphasises the individual and his/her agency.

The concept of agency has been defined as ‘the ability to act’ which means an emphasis on the actions and intentions of human beings. In this research agency can be conceptualised as the ability to deal with a positive HIV test and the consequences of being HIV positive. As discussed before, men seem to respond differently from women when faced with the news that they are HIV positive. Men appear to, more often than women, face periods, and longer periods, of denial and depression. As was mentioned previously men also appear to start with ART in a later stage of HIV infection than women. These two things may be linked: when someone is unable to accept the HIV-status, and because of this does not seek help, this will result in either starting with ART at a later stage of infection, or in the worst case scenario results in death. There may be cultural reasons (macrosystem) as well as a less direct access to social and health services (exosystem) why men access ART at a later stage than woman. However, what is relevant here are not so much the underlying reasons as to why this may be the case, but instead the effects it has: a person’s attitude, beliefs, emotions, and aspirations are strongly related to the choices and actions a person undertakes.

In the first part of this chapter a case study was discussed in which a woman explained that she knew she was at risk of being HIV positive due to her previous multiple sexual relationships. This knowledge and her knowledge about HIV and ART combined with her pro-active attitude resulted in her going for VCT. Through this she discovers she is HIV positive prior to her having experienced any negative consequences on her physical health. In fact, her health never really deteriorates and she starts ART without facing any severe health issues. A less proactive attitude may have resulted in less favourable outcomes. Had she become ill (body), she may have also faced emotional problems (spirit) and possible a less positive attitude towards HIV and ART (mind). Additionally, becoming ill may have resulted in her losing her job which may have impacted her human, financial, physical, and social resources. Finally, being the sole breadwinner of the household this would have have impacted the household as a whole (microsystem) and finally may also have impacted other microsystems she is part of. And also would have had serious consequences for the future education of her daughter.

Returning to the differences between men and women it was seen that women appear to have a more open attitude and positive attitude towards living with HIV and towards ART intake and adherence. In Zambia men are typically the bread winners and as such responsible for the household income. Women instead should look after the home front and take the responsibility to raise the children. Many women in this research reported that their husbands often did not actually bring their salaries home and even when they did the women still often needed to supplement this income as it would be insufficient for the family to live on. This however is of little to no influence on the importance than men hold to being able to work. As such, when men become ill they often report that they feel depressed: by not being able to work they are not able to contribute to the family income and this results in men feeling worthless. Women instead often report that their feelings of desperation stem from the fact that when they are sick they are unable to look after their families and particularly children. Children are also a source of motivation, for women, to try and recover. The care for children lies with women and as such women are motivated to take ART and recover. Women report that they worry about the fate of their children if they would pass away and that they wish to see their children grow up and have a chance to raise them. Men appear to be less motivated by the fate of their families if they don’t recover than women: this is not to say that men care less but instead that while it appears to positively influence women this is less apparent for men. With men the acceptance and motivation appears to come later in the process. While women are motivated already prior to their recovery men appear to start their acceptance when the recovery process is already on the way. When men feel their strength recover and are able to start working a little bit they also recover their sense of self-worth: it is as this time that they start to accept their status and develop hope for the future.
A sense of self-worth and being able to contribute to society also seems to go hand in hand with stigma, or feelings of stigma. Many people report that they were stigmatised and many people also report that they suffered from self-stigma. Feelings of guilt, shame, fear, and hopelessness are often experienced by people when they first learn that they are HIV positive. These feelings can both stem from reactions from a person’s environment but can also come from the individual themselves: people often feel that they are not able to contribute when they are ill and as such are not fulfilling the roles that they feel society expects from them which makes them feel like a burden to others. In some cases people indeed are stigmatised and they find a lot of negativity in their surroundings. However, many people also report that their families supported, loved, and cared for them when they were ill. Clearly the way people experience and understand their HIV status is linked both to their own attitude and to the attitude of the people around them (microsystem(s)).

After people recover many report that they start becoming open about their status. Disclose of someone’s HIV status can be seen in the light of a pro-active attitude towards life and living with HIV, however might also be a consequence of someone being embedded in positive social relations. When people recover physically and are able to return to work and look after their families the stigma they experienced appears to disappear. They themselves start feeling more able to contribute to their family, which adds to their feeling of self-worth. At the same time they have started to accept their HIV status and see a future for themselves and their families. Through ART they now feel they are able to have a future. Being open about one’s status and sharing this with others appears to help people in a number of ways. They are able to share and talk about their experiences which further helps them to come to terms with their status and life on ART. They are able to meet and talk to people who are also HIV positive, allowing them to feel a sense of community: they are not alone. And finally by talking and assisting others people are able to find a positive and useful side to their HIV status.

From the above the importance of the human body, mind, and spirit can be seen. However, it also demonstrates that this should be placed within the everyday experiences in the different microsystems and the mesosystem. These systems are in turn related to the exo- and macrosystems which have an important influence on the everyday environments of PLHIV and their households. This influence is not only on the body, mind, and spirit but also on the human, financial, social, and physical resources. To conclude, this thesis tried to merge three models to examine the everyday life and well-being of PLHIV and their households. The examination of only one of the three models was found to be insufficient in understanding the life trajectories of PLHIV and their households. Instead, through the combination of the different models provides a more holistic overview. This research would like to conclude with a new proposed model to examine how HIV affects people, their households, in the past, current, and the future.

![Combining three models](image-url)

*Figure 8.6: Combining the EST, Livelihoods Pentagon, and BMS model*
Chapter 9 – Conclusions and Recommendations

9.1 Introduction

This final chapter includes the conclusions and recommendations of this thesis. In Chapter 2 a number of research questions were formulated on the basis of the following research aim:

To provide an insight into the impact of ART on the well-being of HIV positive individuals and their households in Lusaka, Zambia.

Chapter 4 provided a summary of research conducted by the author in 2010: this chapter serves to show that socio-economic differences between PLHIV and their households and the general population exist. In Chapter 5 an overview of the demography of the study population was given during the fieldwork period in 2012. In addition, Chapter 5 provides an insight into the current (2012) socio-economic status of PLHIV and their households as well as an insight into the physical and mental health of PLHIV. Chapter 6 focused on the changes that have occurred between 2010 and 2012 for a number of respondents and their households. Chapter 7 introduced the temporal changes and focused on how certain factors (before illness and at the start of ART) influence the personal and socio-economic (current) outcomes of PLHIV and their households. Chapter 8 focused on the individual trajectories that PLHIV went through, from before their illness to now. The first part of the chapter focused on how PLHIV understand and experience their current lives. Finally, the second part of Chapter 8 discussed the interconnectedness of the different aspects of the theoretical models. This last section aims to provide a more holistic understanding of the well-being of PHIV.

In this final chapter the conclusions and recommendations from this thesis will be given. The main findings are presented in section 9.2 of this chapter. This will be followed by section 9.3 that focuses on the implications for theory. And finally the last section will look at the overall main conclusions of the thesis and will conclude with a number of recommendations.

9.2 General Findings

PLHIV on ART, and their households, in Lusaka, Zambia, were found to differ socio-economically from non-PLHIV, and their households. After the initiation of ART people rapidly recover their physical health, however their livelihoods lag behind. Even after 4-6 years people had not managed to reach the socio-economic levels of non-PLHIV in the same area.

Focussing on the PLHIV and their households that took part in this research it was seen that the study population has been impacted negatively by the HIV epidemic. From Chapter 5 it can be seen that the population pyramid deviates from what would normally be expected in a developing country: there are visible gaps in the age groups 25-49 years and 0-4 years. The male to female distribution also deviates from what would be expected in Zambia. For the age group 25 to 49 years the male to female ratio was 1:1.5. In Kalingalinga it was 1:1.3 and in Roma N’gombe this was 1:2.2. In terms of marital status it could be seen that just over 15% of all the adults was widowed, and that this was 20% amongst the age group 25-49 years. Roma N’gombe has a particularly high number of widows: just under 20% amongst all the adults and 30% in the age group 25-49 years. 45.6% of all the...
children were found to be orphaned: 72% of these were paternal orphans. Roma N’gombe is home to the majority of the orphans: 60.2% of all the children who can be categorised as orphans lived in Roma N’gombe.

Reflecting on the stories found in chapter 8 the above conclusions were confirmed. Many people talked about death and experienced or heard of someone in their surrounding having died. Many people report being widowed in the past. The stories also made clear that while someone may now be married this does not necessarily mean that they have not lost a partner in the past. Children as such, may now be living with two parents but this does not mean they are living with their biological parents. The finding regarding the relatively high number of orphans is as such confirmed in the case stories. There also a number of virtual orphans (children whose father or mother may still be alive but who no longer have any contact with this parent). The case stories also highlighted that, women in particular, are motivated to adhere to the ART in order to regain their health and look after their children. Several women told stories about their partners who did not accept their HIV status and eventually died of HIV related conditions.

In Chapter 6 respondents from Roma N’gombe who were interviewed in 2010 and re-interviewed in 2012 were discussed. From the comparison it could be seen that in two years’ time the percentage of children who were single or double orphans increased, from 38.2% to 54.4%. While in 2010 72.2% of the orphans were paternal orphans this was 82.4% in 2012. Additionally a slight increase in the number of people who were widowed was found, nearly only amongst women. Again, here it is possible that more people lost their spouse but have already remarried. Chapter 6 also showed that the earlier discussed trend regarding the male to female ratio has continued. The increase in widows and orphans in the study group is largely due to the fact that men, rather than women, continue to die. It is women who are losing their partners and children who continue to be orphaned paternally. Increasingly children are no longer living with their biological father and those who are, almost always, also live with their biological mother.

In Chapter 5 the socio-economic situation of households was discussed. From this it could be seen that the socio-economic situation is better in Kalingalinga than in Roma N’gombe. People in Kalingalinga often had better housing, they were higher educated, had a better food intake, higher monthly household incomes, and had better jobs than people in Roma N’gombe.

People in Roma N’gombe (80.7%) received more external assistance than people in Kalingalinga (31.9%). This difference is reflected in, for example, school support. While the same percentage of children is attending school in Roma N’gombe as in Kalingalinga it should be noted that this was made possible through external support. 48% of the children who were attending school in Roma N’gombe were receiving support with school related costs; this was only the case for 6% in Kalingalinga.

The physical health of people in Kalingalinga appears either slightly better or the same compared to people in Roma N’gombe. However, emotionally PLHIV in Roma N’gombe are reporting more positive scores than PLHIV in Kalingalinga. People in Roma N’gombe appear to be less emotionally hindered, generally feel better, and have a more positive outlook on life and their general health. In Chapter 5 a possible reason as to why people in Roma N’gombe may have a more positive outlook, where this may not be expected seeing that their socio-economic situation is actually worse, was given. There it was suggested that one possible explanation may actually lie in the additional external support, not so much in material support, but in terms of psycho-social support. Roma N’gombe HBC may often lack funds, just like Kalingalinga HBC, but is more active and successful at organising other funds as well as organising activities. In Chapter 8 the relation between support and counselling in relation to positive attitude and emotional well-being was looked at.

In Chapter 8 it was seen that support and care for PLHIV can come from a variety of places and people. One of the possible places where this support and care is offered is at HBC projects. HBC projects offer direct support when people are ill, however can also play an important role more indirectly on the long term. It was seen that
PLHIV on ART found much comfort in knowing that they are not alone in being HIV positive and that they belong to a community where they can share their story. Support groups and counselling is a big part of this. Being part of a community or an active HBC, which is strong in organising support group sessions, can influence people’s emotional well-being.

Going back to Chapter 6 in which findings from 2010 and 2012 were compared it could be seen that in terms of employment the situation improved between 2010 and 2012. The percentage of PLHIV who were working for payment/profit increased from 52.6% in 2010 to 63.2% in 2012. Also the main source of income improved over the two years: where 38.6% was dependent on paid work in 2010 this was 53.7% in 2012. Similarly the percentage of people who were dependent on piecework (the most insecure type of income source) dropped from 31.6% in 2010 to 9.3% in 2012. Finally, the average household income has also increased.

A conclusion in 2010 was that people and their households need time to recover. The longer people had been on ART the more they, and their households, appeared to recover. The results, presented in Chapter 6, support this conclusion. In addition, this trend continues for a long time after the initial start of ART. In this chapter it was shown that even after 6-7 years of ART improvements are still visible.

In Chapter 7 the various stages that people have gone through were discussed. The chapter provided an insight into the current socio-economic and physical and mental well-being outcomes of ART. It also looked at the trajectory that people went through and showed that the situation indeed first deteriorates (start ART) but then does improve. However, it was also seen that the current situation was not the same as it was before people became ill.

A number of factors that may influence the recovery of PLHIV on ART were discussed by looking at how situations changed over time, what physical condition people were in at the start of ART, and in the opportunities that people have to recover that what they have lost. There is evidence that suggests that, in terms of physical health, for people who start with ART in the early stages of the HIV infection the recovery process will be quicker and that they will recover more fully than those in a more advanced stage of HIV infection. Medical evidence suggests that low CD4 counts at the start of ART reduce the chances of a full physical recovery. When people do not recover fully physically this also means that they will be less able to work. In Chapter 7 it was seen that people with a CD4 count below 200 at the start of ART were more likely to have lost their employment at the start of ART. They also less often recovered their employment situation after starting with ART. Lower CD4 counts also led to lower incomes and households owned less assets.

Comparing employment over time showed that the situation before employment and currently on first hand looked similar. The percentage of PLHIV that were working for payment/profit had initially dropped to 27.2% during the period when people started with ART, but had been regained over time (before illness this was 67.5% and currently it is 72.8%; see section 7.3). However, on closer inspection it was seen that while people were regaining their ability to work for payment/profit the type of work they were currently doing was not the same as they were doing prior to their illness. The number of people working in formal and informal employment had decreased and the number of people now having their own business or doing piecework had increased.

When looking at Chapter 7 and 8 it was seen that early initiation of ART can indeed prevent people from becoming very sick and losing their employment. It was also seen that it was difficult for people to regain their employment after they recovered.

In Chapter 7 the employment situation for PLHIV in Roma N’gombe and Kalingalinga was discussed. From this it could be seen that far more respondents in Roma N’gombe (49%) were not working for payment/profit than in Kalingalinga (14%). Respondents in Kalingalinga were also far more often employed in formal (19%) and informal (33%) employment than respondents in Roma N’gombe (respectively 4% and 9%). A similar situation was found
prior to the respondents’ illness where respondents from Kalingalinga were more often formally or informally employed than respondents from Roma N’gombe. The number of respondents involved in formal and informal employment in Kalingalinga was currently found to currently be almost the same. In Roma N’gombe instead a stark decrease in the number of people that are currently formally or informally employed was seen: before illness 12% of the respondents were formally employed and 23% was informally employed, currently this was found to be respectively 4% and 9%.

Chapter 7 showed that already prior to illness people in Roma N’gombe were facing a more difficult employment situation than people in Kalingalinga. At the start of ART the employment situation of people in Roma N’gombe was worse than in Kalingalinga where 81% of the respondents in Roma N’gombe was not working for payment/profit at the start of ART compared to 68% in Kalingalinga. Additionally the type of employment that people were engaging in was, even, at the start of ART better in Kalingalinga than in Roma N’gombe : 20% of the respondents in Kalingalinga, at the start of ART, was formally or informally employed while in Roma N’gombe no one was formally employed and just 2% was informally employed.

Seeing the socio-economic differences found in Chapter 5 it is not surprising that the employment situation for people in Kalingalinga is better than that of people in Roma N’gombe. In Chapter 8 it was seen that when people recover they do indeed seek employment. However, finding a job is not easy. When people live in a location where less jobs and potential business opportunities are available (Roma N’gombe) it is then not entirely surprising that people here also find it more difficult to recover what they have lost. In Kalingalinga 46% of the respondents is currently doing the same or similar work to what they were doing prior to their illness, this is only 24% in Roma N’gombe. Comparing with Kalingalinga, three times as many people in Roma N’gombe went from working for payment/profit prior to their illness to currently not working. The percentage of people who were working for payment/profit before illness and were able to continue doing so at the start of ART is higher in Kalingalinga (28%) than in Roma N’gombe (14%). After the start of ART people are expected to regain their physical health and in time should be able to return to work. This trend is visible. However, the number of people who were not working at the start of ART but have recovered and are currently working is higher in Kalingalinga (55%) than in Roma N’gombe (35%).

In Chapter 8 it was shown that when people become very ill this puts a great strain on them and their households. Households face economic difficulties and jobs are lost. In Chapter 7 a number of socio-economic factors were discussed and compared not only between the two geographic locations but also in terms of the CD4 count of PLHIV at the start of ART. CD4 counts can be used as a means to provide an insight into the physical well-being of individuals at the start of ART. This provided the following results. 66% of the respondents in Kalingalinga with a CD4 count of 200 and above was working both prior to their illness and currently, compared to 46% in Roma N’gombe. Respondents with a CD4 count of below 200 were also less likely to be working at the start of ART than people with a higher CD4 count. People with a CD4 count of 200 and above worked both prior to their illness and currently, compared to 46% in Roma N’gombe. Respondents with a CD4 count of below 200 were also less likely to be working at the start of ART than people with a higher CD4 count. People with a CD4 count of 200 and above were also more likely to regain their employment than people with a CD4 count of below 200.

In terms of income it was seen that Roma N’gombe has lower mean incomes than Kalingalinga. Furthermore comparing income levels to CD4 count at the start of ART shows that household income is affected by the respondent’s CD4 count at the start of ART. Respondents with a CD4 count of 200 and above currently have higher average household incomes (€117) than people with a CD4 count of below 200 (€95). Looking at the differences in household income level compared to CD4 count in Kalingalinga provides us with a similar trend. Average household income in Kalingalinga is higher where the respondent started with ART with an initial CD4 count of 200 and above (€122 compared to €108). In terms of assets it was seen that households where the respondent had a CD4 count of 200 and above at the start of ART were more likely to own specific assets and on average own more assets than households where the respondent started with a CD4 count of less than 200.
In Chapter 8 results were presented that concur with the above scenario. People who went through a period of illness had more to recover from and had lost more. In one case story a respondent explains how she never fell ill and continued working even when she started with ART. She started with ART early and had a quick recovery, she never lost her employment, and she explains that life is much the same as it always was. In other case stories we can see how people lost their employment due to illness and found it impossible later to regain the same employment. In one case story the respondent manages to be employed by the same boss, his job is however not the same as it was before his illness, nor is his income. In another case story it was seen how after recovery the respondent does find employment but that this is not comparable to the employment he was in before his illness. Regaining employment does not mean it is the same employment and as such also not the same income.

In Chapter 7 people were asked to grade their life over three periods and it was seen that in terms of physical and mental well-being people graded their life the lowest at the start of ART. The scores given currently have improved when compared to how they felt at the start of ART. However, they remain lower than the scores prior to their illness. Comparing these life scores between Kalingalinga and Roma N’gombe shows a similar pattern. However, respondents in Roma N’gombe give higher grades to their life currently (8.14) and before illness (9.08) than people in Kalingalinga (respectively 6.86 and 8.53). Respondents in Roma N’gombe instead give lower grades to their life at the start of ART (4.65) compared to respondents in Kalingalinga (5.89).

Respondents were also asked to describe their general health: people were asked to choose which category (Excellent=1, Very Good=2, Good=3, Fair=4, or Poor=5) best described their general health. The mean and median score for people in Roma N’gombe was very good (median=2, mean=2.21) compared to good in Kalingalinga (median=3, mean=3.1). In Chapter 5 it was seen that the physical health for people in Roma N’gombe and Kalingalinga was almost the same while in terms of mental well-being people in Roma N’gombe scored higher than people in Kalingalinga. When taking CD4 count into consideration in Chapter 7 the following can be noted: respondents with a CD4 count of 200 and above at the start of ART reported higher general health scores than people with a CD4 count of less than 200.

### 9.3 Implications for theory

The models that were introduced in this thesis aim to provide a holistic understanding of the well-being of PLHIV. In order to do this it is important to place the individual at the centre of the research and take into consideration an individual’s experiences, emotions, aspirations, opportunities, and abilities. In addition, this then must be placed into a larger context which includes the direct surroundings of individuals (microsystems) as well as the interactions that exist in these surroundings (mesosystem). Finally, other indirect influences on the individual must be considered; such as the health care system (exosystem) or the gender specific roles that are expected of the individual (macrosystem).

Placing the individual within an ecological model (the EST model) allows for a better understanding of how a person functions within his/her surrounding systems and is both able to influence these and is influenced by these. This thesis showed the importance of the everyday life experiences of PLHIV and how this influences the way how PLHIV view and experience their well-being. The microsystem, and the interaction between the microsystem (=mesosystem), is the realm in which most everyday life experiences take place and this plays a large role in the well-being of individuals. The BMS model which was placed within the individual level allowed for a closer inspection of the individual. It was seen that the various aspects of the BMS model are strongly related to each other and may greatly influence the agency (ability to act) of the individual. Finally, by placing the resource pentagon from the livelihood framework into the EST the various resources can be examined within the different spheres that the individual is influenced by and can influence.
The importance of temporal context within these three models was found to be very important in understanding the lives and the well-being of PLHIV. Through focusing on the chronosystem of the EST model and placing both the BMS model and the resource pentagon within the chronosystem a fuller understanding of life trajectories was sought. To conclude, this thesis merged three models to examine the everyday life and well-being of PLHIV and their households. The examination of only one of the three models was found to be insufficient in understanding the life trajectories of PLHIV and their households. Instead this research finds that, through the combination of the different models a more holistic understanding of the well-being of PLHIV can be provided. This research would like to conclude with a new proposed model to examine how HIV affects people, their households, in the past, current, and the future.

Combining three models

![Combining three models](image)

**Figure 9.1: Combining the EST, Livelihoods Pentagon, and BMS model**

### 9.4 Conclusions and Recommendations

The research in this thesis has shown that while there are similarities to each individual story/trajectory there are also many differences. The situation for PLHIV and their households is not uniform. Over time PLHIV continue to recover after the start of ART and this continues for many years. Additionally, it was seen that certain things cannot be recovered and that while ART is now readily available this does not mean that all the impacts of the HIV epidemic have been mitigated.

Recovery processes are different for each individual and their household. While some people have been very ill and have lost their jobs, assets, and even their partners, others started with ART while they were still healthy and able to work. After people start with ART the recovery process can start – for some life is much the same as prior to their illness, while others have lost everything and will never really get back the life they had prior to their illness. From this it is clear that the less someone loses the less they will later need to recover.

Starting ART at a late stage in the HIV infection has numerous disadvantages, some of which are long lasting. Lower CD4 counts at the start of ART have been identified to lead to higher mortality and loss to follow up (LTFU) (Wanyeki et al. 2011; Muhula, 2012, Meyer-Rath et al. 2010, Cornell et al., 2009a) amongst patients. Becoming very ill and starting with ART with a low CD4 count not only has an immediate effect but may also impact the physical health of individuals years after they have started with ART. There is mounting medical evidence
suggesting that the later in the disease progression ART is started the less likely it is that a full recovery will be made. It becomes less likely that CD4 counts of 500 and above, which is the minimum CD4 count that is required for a good functioning immune system, are reached, even years later, when people start with ART with a CD4 count of under 200. Sabin and Phillips (2009) discuss the long term effects of when to start with ART. one of the findings that they discuss reports that people who started with ART with lower CD4 counts also appear to have lower CD4 counts 7 years after the initial start of ART, compared to people with higher CD4 counts at the start of ART (see Gras et al). People who start with ART with a CD4 count of above 350 appear to have a far higher chance of fully regaining their physical health. Meyer-Rath et al. (2010) found that “mortality and LTFU decreased with both increasing CD4 cell count and time on ART”.

In addition to the long term consequences this has on the physical health of individuals there are also immediate consequences. People who are ill are unable to work and as such are unable to contribute to the household’s participation in the labour market. Moreover, people who are ill often also need assistance and people to take care of them. This directly impacts the labour resources of the households. Whilst being unable to work and needing assistance and care, the households’ financial resources are often also affected. Once the household’s financial resources are affected this most likely will eventually also impact the other resources in the household.

Losing a job and selling assets is non-reversible. Once a job has been lost it is no longer available and as such once a person has recovered physically this does not mean he/she can simply return to their old lives. Jobs are scarce in Zambia and not easily replaceable. Depending on a person’s resources, his/her social network, and even his/her geographic location a person may be more or less successful at securing new employment. Where people are unable to find employment they can try and set up a business – however here too the skills of the individual as well as the opportunities in the area will largely define the success of the business. Moreover, starting a business can be costly and not everyone will be able to do so. Particularly when looking at vulnerable households which have just gone through a severe period of shock it is often unlikely that any finances will be available to set up a business.

Household where PLHIV did not become severely ill and where people did not lose their jobs are doing better (on average) than households where PLHIV did become severely ill. Those people who had a formal paid job prior to their illness and managed to keep this job during the time that they started with ART, today are all currently still holding formal paid jobs. Instead less than half of the respondents who had a formal paid job prior to their illness but lost it at the start of ART today have a formal paid job. This situation is worse in Roma N’gombe than in Kalingalinga where it seems that people in Kalingalinga have more job and business opportunities than people in Roma N’gombe.

There are multiple reasons to suggest that people should start with ART early. The most obvious reason has to do with their physical health, both immediately as well as on the long run. Starting with ART in a late stage of HIV infection increases the morbidity and mortality of PLHIV. In addition, as previously mentioned, people’s physical health appears to recover less when people start with a low CD4 count than when people start with a high CD4 count. The WHO recently published new guidelines which aim to start treatment earlier; where previous guidelines suggested that people should start with treatment when their CD4 count was below 350 the new guidelines advise to start treatment when CD4 counts are below 500 (see WHO, 2013). In the United States the medical guidelines go a step further and suggest that everyone who is found to be HIV positive should immediately start on medication. Recently discussions in the Netherlands, and other European countries, are also steering towards the US guidelines. There is now increasingly more medical evidence to suggest that starting treatment earlier is advisable.

This thesis would like to add on to the above conclusions. Evidence from the research conducted for this thesis suggests that in addition to the medical benefits there are also socio-economic reasons why starting treatment
early is advisable. This is the main conclusion of this thesis. If people do not become sick before they start their recovery then there will also be less to recover. If people are able to continue working then they will not lose their jobs and need to find new employment once they physically recover. When people don’t lose their jobs the household’s financial resources will also not be affected. This in turn means that people will not need to sell assets, take children out of school, etc.

There is some evidence to suggest that much of the stigma and self-stigma stems from the idea that a person is not being productive. The person, when ill, unable to work, and in need of assistance, can be seen as a burden, and more often view themselves as a burden. Men report that they feel worthless and are depressed when they are unable to support their families. For women feelings of failure and depression particularly stem from the idea that it is their job to look after their family. When either is unable to fulfill this role this can lead to stigmatisation or self-stigma. When people recover physically much of the reported stigma disappears. As such, if people could start treatment prior to their physical health having been affected then this period of depression and feelings and experiences with stigma may partly be avoided.

Social support systems are of vital importance to PLHIV. While there is only limited evidence results in this thesis suggest that counselling, support groups, and external support for PLHIV can have a positive outcome for people’s mental well-being. Through the sharing of experiences, being able to share one’s story, helping and advising others, and being part of a community people are able to come to terms with the HIV positive status. Through advising and helping others people regain a sense of self-respect which allows them to have a more positive attitude towards their HIV status.

Zambia has a traditional support system within the extended family. However, not only is this social support system already under a lot of stress it also cannot offer all of the support PLHIV need. Particularly in terms of psycho-social support in the form of counselling and support groups people need external support. Currently there are a limited number of places where people can receive such assistance. One of the places people can find this support is within the HBC projects. While the traditional role of HBC has changed with the coming of ART this does not mean that HBC projects no longer play a role. Evidence in this thesis suggests that HBC projects can play a vital role in the lives of PLHIV on ART. Through counselling and support the mental well-being of PLHIV can be influenced positively.

In this thesis it was also seen that the role Home Based Care (HBC) projects play differ depending strongly on the ability of HBC projects to be creative with resources, act independently, and find external (financial) resources. At the moment the difference in success seems to be dependent on the leadership and commitment skills of the individual HBC coordinators. If individual HBC projects are more financially stable the care, assistance, and support that PLHIV receive can also be more constant. This research recommends that HBC projects should be continued and supported. Currently the Community Home Based Care (CHBC) programme has a large number of HBC projects which means that the few available resources have to be shared amongst many project sites. Considering that Lusaka is not uniform in terms of socio-economic level and PLHIV will have different needs it is recommended that the CHBC takes this into consideration when distributing the available resources.

The main recommendations for future policy and interventions of this thesis are:

- Start ART in an early stage of the HIV infection, so PLHIV and their households do not lose their socio-economic position.
- The Home Based Care approach, although changed, is still important in order to improve the mental well-being of PLHIV and should therefore be continued and supported with an additional focus on the most vulnerable and poorest communities.
The main recommendations for future research of this thesis are:

- There is increasing evidence that men are accessing ART disproportionately less than women. In this research fewer men than women were found to be on ART. In addition it was seen that the number of paternal orphans increased between 2010 and 2012. Limited research has been conducted on this subject and in particular on the underlying reasons why so many men are not accessing ART. It is recommended that future research pays attention to this difference. Why are there disproportionately fewer men than women accessing ART programmes in Sub Saharan Africa? In addition to the underlying reasons why, research into the consequences of this is also needed. With fewer men in ART roll-out programmes, more men starting late, more men stopping with ART, and ultimately more men dying, there are also fewer men available in society, their communities, and their families. Women are already in a vulnerable position, often they too are HIV positive and on ART. If their husbands fall ill the burden of care will fall on them, additionally if their husbands die they will also have to take over the full responsibility as head of the household. As such, fewer men accessing ART is affecting not only the health of individuals but is also affecting the welfare and well-being of households, communities, and ultimately entire societies.

- In order to understand the well-being of PLHIV a holistic approach should be taken. In this research it was seen that by using a combination of models a broader understanding of the well-being of PLHIV on ART can be found. It is recommended that future research incorporates a holistic understanding. And specifically, should incorporate temporal context into the research.

- The research for this thesis was conducted in an urban context. More research into the rural context is required. In a rural context physical resources will be less important while natural resources will be more important. In addition, the social networks and the impact of the exosystem and macrosystem may be different. As such, it is recommended that research into rural areas takes these differences into consideration.

- A shift in how HIV and ART is viewed in the community is visible. ART is becoming more embedded in society and HIV is increasingly becoming a chronic illness instead of a death sentence. This shift is changing people’s view of HIV and ART and may impact PLHIV. It is recommended that this social change is studied in future research.
Bibliography


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COVER SHEET – RESPONDENT

Case number: ________

Day: ____ / ____ / _____

Name Interviewers: __________________________________________

Statement of confidentiality: This questionnaire is part of a research project on the well-being of people. All information gathered is confidential and will be used only for research. Your identity and that of your household will not be revealed to anyone. Nobody will be able to identify you or use the information against you.

To the interviewer: The above statement of confidentiality was read to the respondent and the respondent has agreed to participate in the interview.

☐ Please tick the box.
### Introduction

**WE ARE INTERVIEWING PEOPLE WHO ARE HIV POSITIVE AND ARE RECEIVING ANTIRETROVIRAL THERAPY. THE AIM OF THESE INTERVIEW IS TO GAIN A BETTER UNDERSTANDING ABOUT THEIR LIVES. WE WILL BE ASKING QUESTIONS ABOUT YOUR LIFE AS IT IS NOW, BUT ALSO ABOUT OTHER STAGES.**

### Part 1: General Story Line

**WE WOULD LIKE TO ASK YOU A NUMBER OF QUESTIONS ABOUT YOUR LIFE. HOW YOU ARE DOING NOW, HOW YOU DISCOVERED YOU WERE HIV POSITIVE AND CAME TO START WITH ART, AS WELL AS ABOUT HOW YOUR LIFE WAS BEFORE YOU BECAME ILL.**

**Could you please tell us your life story and the story about your illness?**

**Points of attention:**
- When did the first problems start, when was that
- Was the person working going to school at this time
- When did he or she go to the hospital clinic
- How was it discovered that they were HIV positive
- What happened to the family in those days
- When did they start ART
- How did the person respond to the treatment (be empathetic and ask about things like side effects, whether they are still on the same medication, do they remember perhaps their CD4 count then and now)
- How was the situation during illness and start of the treatment
- Family history: marriage status (if widowed or separated also refer to this and ask how this happened)

| 1. |  |  |
### Part 2. Household Profiling → To be complete for: Adults! (→ 1 Page!!)

Ensure that the respondent is the first person on the sheet below!

How many adults live in this household?
(Assume the respondent to name all the adults (18 years or older) and children (younger than 18 years) in the household and note this down, count them and make sure to double check this with the respondent). (People who are visiting are NOT counted. Ensure the respondent is aware of this. People need to live in the household a minimum of 4 days a week before they are counted)

To be completed for all adults who make up the household (all people of 18 and above who live here and usually eat together)

<table>
<thead>
<tr>
<th>No.</th>
<th>Name</th>
<th>Marital status</th>
<th>Relationship</th>
<th>Sex</th>
<th>Age</th>
<th>Education</th>
<th>Work</th>
<th>Financial contribution</th>
</tr>
</thead>
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</tbody>
</table>
### Part 2. Household profiling! → To be complete for: **Children! Page 1 (±2 Pages!!)**

**How many children live in this household?**
(Ask the respondent to name all the children younger than 18 years in the household and note this down, count them and make sure to double check this with the respondent) (People who are visiting are NOT counted. Ensure the respondent is aware of this. People need to live in the household a minimum of 4 days a week before they are counted)

**To be completed for all children who make up the household (all people below 18 who live here and usually eat together)**

<table>
<thead>
<tr>
<th>No.</th>
<th>Name</th>
<th>Marital status</th>
<th>What is ...‘s marital status at the moment?</th>
<th>Relationship</th>
<th>What is ...‘s relationship to the head of the household?</th>
<th>Sex</th>
<th>What is ...‘s sex?</th>
<th>Age</th>
<th>What is ...‘s age?</th>
<th>Education</th>
<th>Does ...‘s attend any institution of education at the moment?</th>
<th>Education</th>
<th>Who pays the school fees for ...?</th>
</tr>
</thead>
</table>
**PART 2** CONTINUED... TO BE COMPLETE FOR CHILDREN! PAGE 2 (➔2 PAGES!!)

**TO BE COMPLETED FOR ALL CHILDREN (YOUnger THAN 18 YEARS) IN THE HOUSEHOLD**

<table>
<thead>
<tr>
<th>Work</th>
<th>Parents</th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>What type of work does .......... do?</td>
<td>With which of its own (biological) parents is .......... living?</td>
<td>*ask if previous answer was: 3 or 4</td>
<td>*ask if previous answer was: 2 or 4</td>
</tr>
<tr>
<td>1 – work around the house</td>
<td>1 – with both parents</td>
<td>Why is .......... not staying with his/her mother?</td>
<td>Why is .......... not staying with his/her father?</td>
</tr>
<tr>
<td>2 – work for pay/profit</td>
<td>2 – with mother</td>
<td>1 – mother is no longer alive</td>
<td>1 – father is no longer alive</td>
</tr>
<tr>
<td>3 – too young to work</td>
<td>3 – with father</td>
<td>2 – mother is alive, state reason she is not living with this child.</td>
<td>2 – father is alive, state reason he is not living with this child.</td>
</tr>
<tr>
<td>4 – not available to work</td>
<td>4 – child is not living with parents.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

20 | Reason not living with mother: | Reason not living with father: |
21 | Reason not living with mother: | Reason not living with father: |
22 | Reason not living with mother: | Reason not living with father: |
23 | Reason not living with mother: | Reason not living with father: |
24 | Reason not living with mother: | Reason not living with father: |
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26 | Reason not living with mother: | Reason not living with father: |
27 | Reason not living with mother: | Reason not living with father: |
28 | Reason not living with mother: | Reason not living with father: |
29 | Reason not living with mother: | Reason not living with father: |
30 | Reason not living with mother: | Reason not living with father: |
### Part 3: Physical Surrounding

3. **Who owns the house you live in?**
   - (1) Own house → Go to question 7!
   - (2) Landlord (rented house) → Go to question 5!
   - (3) Other: ____________ (specify) → go to next question!

4. **Do you or anyone else who is part of the household pay rent for the house?**
   - (1) yes → Go to next question
   - (2) no → Go to question 7!

5. **How much does the household pay for rent?**
   K ____________ per ____________

6. **Does the rent include the cost for water?**
   - (1) yes → Go to next question
   - (2) no → Go to next question!

7. **How much money does the household spend on water?**
   K ____________ per ____________

8. **What is the main source of water for your household?**
   - (1) running (piped) water in the house
   - (2) running (piped) water to the yard/plot
   - (3) public tap
   - (4) private borehole
   - (5) public borehole
   - (6) private well
   - (7) public well
   - (8) other: ____________ (specify)

9. **Does your house have access to electricity?**
   - (1) yes → Go to next question!
   - (2) no → Go to question 13!

10. **Does the rent include the cost for electricity?**
    - (1) yes → Go to question 13
    - (2) no → Go to next question

11. **Does your household spend any money on electricity?**
    - (1) yes → Go to next question!
    - (2) no → Go to question 13!

12. **How much does your household pay for electricity?**
    K ____________ per ____________

### Part 4: Health and Well-being Baseline

13. **If you could give you life a grade between 1 and 10, where 10 is the highest and 1 is the lowest, what grade would you give it?** ____________

14. **In general, would you say your health is:**
   - (1) Excellent
   - (2) Very good
   - (3) Good
   - (4) Fair
   - (5) Poor
15. The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much?

   a) Does your health limit you (1) a lot, (2) a little, or (3) not at all, in light/medium activities, such as moving a table, sweeping, or hanging up washed clothes?
      □ (1) Yes, limited a lot
      □ (2) Yes, limited a little
      □ (3) No, not limited at all

   b) Does your health limit you (1) a lot, (2) a little, or (3) not at all, in heavy/hard activities, such as climbing up a steep hill, walking large distances, carrying water, breaking rocks, or collecting firewood?
      □ (1) Yes, limited a lot
      □ (2) Yes, limited a little
      □ (3) No, not limited at all

16. During the past 4 weeks, how much of the time have you had any of the following problems with your work of other regular daily activities as a result of your physical health?

   a) In the past 4 weeks, my physical health has caused me to accomplish less than I would like:
      □ (1) all of the time
      □ (2) most of the time
      □ (3) some of the time
      □ (4) a little of the time
      □ (5) none of the time

   b) In the past 4 weeks, my physical health has limited me in the kind of work or other activities I perform:
      □ (1) all of the time
      □ (2) most of the time
      □ (3) some of the time
      □ (4) a little of the time
      □ (5) none of the time

17. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

   a) During the past 4 weeks, emotional problems have caused me to accomplish less than I would like:
      □ (1) all of the time
      □ (2) most of the time
      □ (3) some of the time
      □ (4) a little of the time
      □ (5) none of the time

   b) In the past 4 weeks, my emotional problems have limited me in the kind of work or other activities I perform:
      □ (1) all of the time
      □ (2) most of the time
      □ (3) some of the time
      □ (4) a little of the time
      □ (5) none of the time
18. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**
   - (1) Not at all
   - (2) A little bit
   - (3) Moderately
   - (4) Quite a bit
   - (5) Extremely

19. **During the past 4 weeks, how much of the time:**

<table>
<thead>
<tr>
<th></th>
<th>(1) all of the time</th>
<th>(2) most of the time</th>
<th>(3) some of the time</th>
<th>(4) A little of the time</th>
<th>(5) none of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) During the past 4 weeks, how much of the time have you felt calm and peaceful?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>b) During the past 4 weeks, how much of the time did you have a lot of energy?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>c) During the past 4 weeks, how much of the time have you felt downhearted and depressed?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

20. **During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?**
   - (1) Not at all
   - (2) A little bit
   - (3) Moderately
   - (4) Quite a bit
   - (5) Extremely

---

**PART 5: CURRENT SITUATION**

I WOULD NOW LIKE TO ASK YOU SOME GENERAL QUESTIONS. THESE QUESTIONS ARE ABOUT DIFFERENT THINGS REGARDING YOU AND YOUR HOUSEHOLD.

**General**

21. **What tribe does the head of the household belong to?**
   
   ____________________________ (state name of tribe or language)

**Income/nutrition**

22. **Where does the main source of food in the household come from?**
   - (1) buy
   - (2) own farmland
   - (3) from other family members, specify who: ____________________________
   - (4) from well wishers, specify who: ____________________________
   - (4) other: ____________________________ (specify)
23. What are the main sources of income for the household?

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount contributed</th>
<th>Per (day/week/month)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>K.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>K.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>K.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>K.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>K.</td>
<td></td>
</tr>
</tbody>
</table>

24. What is the total average monthly income (if any) of the household? ____________ Kwacha

25. Do you do any work for which you receive money?
   - (2) no  → Go to next question
   - (1) yes → What kind of work do you do?

26. Do you do any work for which you do not receive money?
   - (2) no  → Go to next question
   - (1) yes → What kind of work do you do?

27. Did you have breakfast yesterday?
   - (2) no  → Go to next question
   - (1) yes → What did you have for breakfast?

28. Did you have lunch yesterday?
   - (2) no  → Go to next question
   - (1) yes → What did you have for lunch?

29. Did you have dinner yesterday?
   - (2) no  → Go to next question
   - (1) yes → What did you have for dinner?

30. Does your household ever experience any food shortages?
   - (2) no  → Go to next question
   - (1) yes → Is there a specific period in the year or in the month when you experience food shortages?

31. What source of energy do you use to cook your food?
   - (1) electricity
   - (2) charcoal
   - (3) wood (ensure respondent is not referring to wood chips!)
   - (4) wood chips
   - (5) other:  

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### Household assets

We would like to ask you a couple of questions regarding what kind of things the household owns.

#### Non-productive assets

32. **Does your household own any of the following items, and how many?**

*Ask about ALL items listed!*

<table>
<thead>
<tr>
<th>Item</th>
<th>Owns item?</th>
<th>How many?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  television</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>2  radio</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>3  mobile phone</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>4  mattress (only mattress) → count bed separately!!</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>5  bed (frame) → count mattress separately!!</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>6  blanket</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>7  cupboard</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>8  display cupboard</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>9  sofa chairs</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>10 morris chairs</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>11 bicycle</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>12 kitchen chair</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>13 table</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>14 car (working)</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>15 car (not working)</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
</tbody>
</table>

33. **Does your household own any other items of relevance that were not mentioned?** Namely (ask for amount!)

<table>
<thead>
<tr>
<th>Item</th>
<th>How many?</th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td></td>
</tr>
</tbody>
</table>

#### Productive assets

33. **Does your household own any of the following tools, and how many?**

*Ask about ALL items listed!*

<table>
<thead>
<tr>
<th>Item</th>
<th>Owns item?</th>
<th>How many?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  plough</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>2  knitting machine</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>3  wheelbarrow</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>4  hoe/shovelaxe</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>5  peanut butter machine</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>6  small tools (for example: hammer, screwdriver)</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>7  sewing machine</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
<tr>
<td>8  grinder</td>
<td>□ (1) yes  □ (2) no</td>
<td></td>
</tr>
</tbody>
</table>
Does your household own any other items of relevance that were not mentioned? Namely: (ask for amount!)

<table>
<thead>
<tr>
<th>Item</th>
<th>How many?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

34. Are there any tools or machines that the household has access to but does not own?
   - (2) no → Go to next question!
   - (1) yes → Specify:

<table>
<thead>
<tr>
<th>What tools/machines</th>
<th>Payment involved</th>
<th>Amount:</th>
<th>Per: (hour/day/week)</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ (2) no   □ (1) yes</td>
<td>K.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ (2) no   □ (1) yes</td>
<td>K.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ (2) no   □ (1) yes</td>
<td>K.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ (2) no   □ (1) yes</td>
<td>K.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ (2) no   □ (1) yes</td>
<td>K.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

Physical capital
The next few questions are about food production and land.

Food production/land

35. Does your household produce any food?
   - (2) no → Go to next question!
   - (1) yes → Specify

<table>
<thead>
<tr>
<th>What:</th>
<th>Amount:</th>
<th>Type (kg/bags):</th>
<th>Per (once a year/all year round/etc):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
36. Does your household own any land?
   - (2) no ➔ Go to next question!
   - (1) yes ➔ Specify:
     how much land (specify hectares/acre/s/ha/s):
     what is this land used for:

37. Does your household have access to any land which it does not own?
   - (2) no ➔ Go to question 39
   - (1) yes ➔ please specify
     how much land (specify hectares/acre/s/ha/s):
     what is this land used for:

38. Do you or anyone in your household pay for this land?
   - (2) no ➔ Go to question 39
   - (1) yes ➔ Please specify:
     How much do you pay for the use of the land?
     K______________________ per__________________

39. Does your household own any animals?
   - (2) no ➔ Go to next question!
   - (1) yes ➔ Specify
     | What type of animals? | How many? |
     |-----------------------|-----------|
     |                       |           |
     |                       |           |
     |                       |           |
     |                       |           |
     |                       |           |
     |                       |           |

Social capital

WE WOULD NOW LIKE TO ASK YOU A NUMBER OF QUESTIONS REGARDING ANY ASSISTANCE YOU OR ANYONE IN YOUR HOUSEHOLD MAY BE RECEIVING.

Formal/informal organisations

40. Do you or any members of your family receive help/assistance from outside the household?
   - (2) no ➔ Go to next question!
   - (1) yes ➔ Specify ➔ fill in the table on the next page.
### Additional questions

41. **What are the most important problems you are facing?**

### During illness

### General questions

This section of the questionnaire is about the period when you first started with cART. We would like you to think back the time when you first started with cART. We would now like to ask you a number of general questions regarding cART.

43. **When did you discover you were HIV positive?**
   - Year: __________
   - Month: __________

   *(If respondent does not remember try and ask in which period of the year, was it cold? Was it in the rainy season?)* → **Period of the year:** __________

42. **When did you start with cART?**
   - Year: __________
   - Month: __________

   *(If respondent does not remember try and ask in which period of the year, was it cold? Was it in the rainy season?)* → **Period of the year:** __________

44. **If you could give you life when you first started with cART a grade between 1 and 10, where 10 is the highest and 1 is the lowest, what grade would you give it?** __________
Can you please describe to me: What was your life like when you first started with cART?

(Asist the respondent by referring to their physical well being at the time, their food intake, what they were still able to do, if they needed assistance, how they felt at the time. Also if not mentioned by the respondent ensure to ask about the points written in the answer field below)

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Do you remember what your CD4 count was? □ (1) yes □ (2) no</td>
<td></td>
</tr>
<tr>
<td>What was your CD4 count:</td>
<td></td>
</tr>
<tr>
<td>☐ Would it be accurate to say that you were bedridden when you first</td>
<td>☐ (1) yes</td>
</tr>
<tr>
<td>started cART?</td>
<td>☐ (2) no</td>
</tr>
<tr>
<td>☐ Did you need any assistance?</td>
<td>☐ (2) no → next question</td>
</tr>
<tr>
<td>☐ (1) yes → specify</td>
<td></td>
</tr>
<tr>
<td>What did you need assistance with:</td>
<td></td>
</tr>
<tr>
<td>☐ Were you able to do any work when you first started cART?</td>
<td>☐ (2) no → next question</td>
</tr>
<tr>
<td>☐ (1) yes → specify</td>
<td></td>
</tr>
<tr>
<td>What kind of work you were doing when you first started with cART?</td>
<td>(specify both paid and</td>
</tr>
<tr>
<td></td>
<td>unpaid work)</td>
</tr>
</tbody>
</table>
46. Did the household produce any food when you first started cART?
   - (1) yes → Go to next question
   - (2) no → Go to next question
   - (3) don’t know → Go to question 48

47. Are there any differences in terms of food production between the time you first started taking cART and today?
   - (2) no
   - (1) yes, please specify what is different (type of food, amount, etc.):

48. Were any of the other members (both children and adults) of your household working for pay/profit/money at the time that you first started cART?
   - (2) no → Go to next question
   - (3) don’t know → Go to next question
   - (1) yes → Specify:
     Who was working?

<table>
<thead>
<tr>
<th>Name</th>
<th>Type of work?</th>
<th>Currently doing the same work?</th>
<th>Currently part of the household?</th>
<th>If yes, enter respondent number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

49. Were any of the other members (adults only) of your household NOT working for pay/profit/money at the time that you first started cART?
   - (2) no → Go to next question
   - (3) don’t know → Go to next question
   - (1) yes → Specify:

<table>
<thead>
<tr>
<th>Name</th>
<th>Reason not working?</th>
<th>Currently working?</th>
<th>Currently part of the household?</th>
<th>If yes, enter respondent number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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50. Did your household own/ or have access to any land at the time that you first started with cART?
   - (2) no → Go to next question
   - (3) don’t know → Go to next question
   - (1) yes → Specify:
     How much land:
     | Amount: | Specify hectares/ acres/ lima’s: |
     |---------|---------------------------------|

     What was this land used for:

51. Did your household own any animals when you first started with cART?
   - (2) no → Go to next question
   - (3) don’t know → Go to next question
   - (1) yes → Specify:
     What animals did the household have and how many? (if the respondent cannot remember the exact amount please find out if he/she thinks there are more or less now compared to then and enter this under how many)
     | What type of animals? | How many? |
     |-----------------------|-----------|
     |                       |           |
     |                       |           |
     |                       |           |
     |                       |           |
     |                       |           |
     |                       |           |

52. When you first started with cART what were the biggest problems you were facing?
WE WOULD LIKE YOU TO THINK ABOUT YOUR LIFE TODAY AND YOUR LIFE WHEN YOU FIRST STARTED WITH cART.

Could you please explain what has changed in your life between when you first started cART and how it is now?

(Asist the respondent by asking changes. For example in their physical health, CD4 counts, work/employment situation, family situation, children, food, assistance. Refer to the income and discuss changes. What about their daily routine, how has this has changed. Also ensure that the questions in the answer space are discussed)

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has your physical strength changed?</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td><strong>How has it changed?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has your ability to work changed?</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td><strong>How has it changed?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has your position in the household changed?</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td><strong>How has this changed:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has your food intake changed?</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td><strong>How has it changed?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has the assistance you need/receive changed?</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td><strong>How has it changed?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has your CD4 count changed?</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td><strong>How has it changed?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has your role in the community changed?</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td><strong>How has it changed?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>54.</td>
<td>What do you think are the main benefits of ART?</td>
<td></td>
</tr>
<tr>
<td>55.</td>
<td>What do you think are the main negatives of cART?</td>
<td></td>
</tr>
<tr>
<td>56.</td>
<td>What was the main reason you started with cART?</td>
<td></td>
</tr>
</tbody>
</table>

**Progression of Illness**

**Introduction**
The following section of the questionnaire is about the period before illness. People can start with cART at very different points in their lives and not everyone is suffering from frequent periods of illness at the start of ART.

| 57. | Before you started with cART were you suffering from frequent periods of illness? |
|     | (1) yes |
|     | (2) no |
|     | (3) don't know |

| 58. | Before you started with cART had your physical health been affected (for example: weight loss, weakness)? |
|     | (1) yes |
|     | (2) no |
|     | (3) don't know |
TO BE ENTERED BY INTERVIEWER:

<table>
<thead>
<tr>
<th>Respondent mentioned:</th>
<th>Enter score</th>
<th>Score:</th>
</tr>
</thead>
</table>
| Bedridden at start cART (see question 45) | □ yes → 2  
□ no → 0  
□ don’t know → 1 |        |
| Needed assistance due to health problems (see question 45) | □ yes → 2  
□ no → 0  
□ don’t know → 1 |        |
| Was unable to work at start cART (see question 45) | □ yes → 2  
□ no → 0  
□ don’t know → 1 |        |
| Experienced frequent periods of illness (see question 57) | □ yes → 2  
□ no → 0  
□ don’t know → 1 |        |
| Physical health been affected (see question 58) | □ yes → 2  
□ no → 0  
□ don’t know → 1 |        |

**TOTAL SCORE:**

FOR A FINAL SCORE OF 2 OR MORE ALWAYS COMPLETE THE NEXT SECTION. FOR A SCORE OF LESS THAN 2 (SO 1 OR 0) DON’T COMPLETE NEXT SECTION INSTEAD SKIP ALL QUESTION EXCEPT FOR THE FINAL QUESTION, QUESTION 71.

### Before Illness

#### Introduction

**READ IF → SCORE IS TWO OR MORE & QUESTION 57 IS ANSWERED WITH YES:**

THE FOLLOWING SECTION OF THE QUESTIONNAIRE IS ABOUT THE PERIOD OF YOUR LIFE IN WHICH YOU DID NOT SUFFER FROM ANY FREQUENT PERIODS OF ILLNESS OR BEFORE YOUR PHYSICAL HEALTH WAS IN ANYWAY AFFECTED BY THE HIV VIRUS.

**READ IF → SCORE IS TWO OR MORE & QUESTION 57 IS ANSWERED WITH NO:**

THE FOLLOWING SECTION OF THE QUESTIONNAIRE IS ABOUT THE PERIOD OF YOUR LIFE IN WHICH YOU DID NOT SUFFER FROM ANY FREQUENT PERIODS OF ILLNESS OR BEFORE YOUR PHYSICAL HEALTH WAS IN ANYWAY AFFECTED BY THE HIV VIRUS. YOU HAVE INDICATED THAT YOU DID NOT SUFFER FROM FREQUENT PERIODS OF ILLNESS BEFORE THE START OF CART. IT DOES HOWEVER APPEAR THAT YOUR PHYSICAL HEALTH WAS SOMEWHAT AFFECTED BEFORE YOU STARTED CART. AS SUCH WE WOULD STILL LIKE TO ASK YOU SOME QUESTIONS ABOUT THIS PERIOD.

**IF SCORE IS LESS THAN TWO → GO TO LAST QUESTION.**

WE WOULD NOW LIKE TO TALK TO YOU A BIT ABOUT THE TIME BEFORE YOU BECAME ILL.

59. **If you could give your life before you became ill a grade between 1 and 10, where 10 is the highest and 1 is the lowest, what grade would you give it?**
**Can you please describe to me what was your life like before you became ill/started cART?**

( Assist the respondent by asking about the family situation at this time, their strength, the work/school situation, their marital status, their daily routine, their general health)

**Points of attention:**
- Was the person working/going to school at this time
- Family history: marriage status. What did the household look like at the time
- Typical day

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>19.</td>
</tr>
</tbody>
</table>

**Household labour**

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>61.</td>
<td>Were you working or attending school before you became ill/started cART?</td>
</tr>
<tr>
<td></td>
<td>(2) no → Go to question 63</td>
</tr>
<tr>
<td></td>
<td>(1) yes → Go to next question</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>62.</td>
<td>Can you please explain what kind of work or schooling you were doing?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>63.</td>
<td>Did the household produce any food before you became ill/started cART?</td>
</tr>
<tr>
<td></td>
<td>(1) no → Go to question 65</td>
</tr>
<tr>
<td></td>
<td>(2) yes → Go to next question</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>64.</td>
<td>Are there any differences in terms of food production between the time before you were ill/started cART and today?</td>
</tr>
<tr>
<td></td>
<td>(1) no → Go to next question</td>
</tr>
<tr>
<td></td>
<td>(2) yes, please specify what is different (type of food, amount, etc)</td>
</tr>
</tbody>
</table>
65. Were any of the other members (both adults and children) of your household working for 
profit/money before you were ill/started cART?
☐ (2) no → Go to next question
☐ (3) don’t know → Go to next question
☐ (1) yes → Specify: Who was working?

<table>
<thead>
<tr>
<th>Name</th>
<th>Type of work?</th>
<th>Currently doing the same work?</th>
<th>Currently part of the household?</th>
<th>If yes, enter respondent number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>□ (2) no □ (1) yes</td>
<td>□ (2) no □ (1) yes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ (2) no □ (1) yes</td>
<td>□ (2) no □ (1) yes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ (2) no □ (1) yes</td>
<td>□ (2) no □ (1) yes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ (2) no □ (1) yes</td>
<td>□ (2) no □ (1) yes</td>
<td></td>
</tr>
</tbody>
</table>

66. Were any of the other members (adults only) of your household NOT working for 
profit/money before you were ill/started cART?
☐ (2) no → Go to next question
☐ (3) don’t know → Go to next question
☐ (1) yes → Specify: Who was not working?

<table>
<thead>
<tr>
<th>Name</th>
<th>Reason not working?</th>
<th>Currently working?</th>
<th>Currently part of the household?</th>
<th>If yes, enter respondent number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>□ (2) no □ (1) yes</td>
<td>□ (2) no □ (1) yes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ (2) no □ (1) yes</td>
<td>□ (2) no □ (1) yes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ (2) no □ (1) yes</td>
<td>□ (2) no □ (1) yes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ (2) no □ (1) yes</td>
<td>□ (2) no □ (1) yes</td>
<td></td>
</tr>
</tbody>
</table>

67. Did your household own/have access to any land at the before you were ill/started cART?
☐ (2) no → Go to next question
☐ (3) don’t know → Go to next question
☐ (1) yes → Specify: How much land?

<table>
<thead>
<tr>
<th>Amount:</th>
<th>Specify hectares/acres/lima’s:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What was this land used for:
68. Did your household own any animals before you became ill/started cART?
   □ (2) no → Go to next question
   □ (3) don’t know → Go to next question
   □ (1) yes → Specify:

   What animals did the household have and how many?
   (If the respondent cannot remember the exact amount please find out if
   he/she thinks there are more or less now compared to then and enter this
   under how many)

   What type of animals?    How many?
   ________________________
   ________________________
   ________________________
   ________________________
   ________________________
   ________________________
I WOULD LIKE YOU TO THINK ABOUT THE PERIOD BEFORE YOU BECAME ILL AND HOW THIS GRADUALLY CHANGED TO WHEN YOU FIRST STARTED cART

Could you explain to me how your life changed from before you were ill up to the point that you first started taking cART?

(Aside: assist the respondent by asking changes. For example, in their physical health, work/employment situation, family situation, children, food, assistance. Refer to the income and discuss changes. What about their daily routine, how has this has changed. Also ensure that the questions in the answer space are discussed)

<table>
<thead>
<tr>
<th>Did your physical strength change?</th>
<th>(1) yes □ (2) no</th>
</tr>
</thead>
<tbody>
<tr>
<td>How did it change?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Did your ability to work change?</th>
<th>(1) yes □ (2) no</th>
</tr>
</thead>
<tbody>
<tr>
<td>How did it change?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Did your position in the household change?</th>
<th>(1) yes □ (2) no</th>
</tr>
</thead>
<tbody>
<tr>
<td>How did it change?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Did your food intake change?</th>
<th>(1) yes □ (2) no</th>
</tr>
</thead>
<tbody>
<tr>
<td>How did it change?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Did the assistance you need/receive change?</th>
<th>(1) yes □ (2) no</th>
</tr>
</thead>
<tbody>
<tr>
<td>How did it change?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Did your role in the community change?</th>
<th>(1) yes □ (2) no</th>
</tr>
</thead>
<tbody>
<tr>
<td>How did it change?</td>
<td></td>
</tr>
</tbody>
</table>
Could you please explain what has changed in your life between before you were ill/started cART and how it is now?

(Assist the respondent by asking changes. For example in their physical health, work/employment situation, family situation, children, food assistance. Refer to the income and discuss changes. What about their daily routine, how has this has changed. Also ensure that the questions in the answer space are discussed)

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has your physical strength changed? yes no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How has it changed?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has your ability to work changed? yes no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How has it changed?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has your position in the household changed? yes no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How has this changed:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has your food intake changed? yes no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How has it changed?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has the assistance you need/receive changed? yes no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How has it changed?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has your role in the community changed? yes no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How has it changed?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
THANK YOU VERY MUCH!!!

Do you have any comments, remarks, questions, or suggestions?

ANY OTHER QUESTIONS/REMARKS THE RESPONDENT HAS CAN BE WRITTEN BELOW
Appendix 2: JCTR Basic Need Basket

JCTR BASIC NEEDS BASKET: LUSAKA

April 2010

(A) COST OF BASIC FOOD ITEMS FOR A FAMILY OF SIX IN LUSAKA

<table>
<thead>
<tr>
<th>Commodity</th>
<th>Kwacha</th>
<th>Quantity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mealie meal (breakfast)</td>
<td>64,700</td>
<td>3 x 25 Kg bags</td>
<td>194,100</td>
</tr>
<tr>
<td>Beans</td>
<td>12,700</td>
<td>2 Kgs</td>
<td>25,400</td>
</tr>
<tr>
<td>Kapenta (Siyavonga)</td>
<td>75,000</td>
<td>2 Kgs</td>
<td>150,000</td>
</tr>
<tr>
<td>Dry Fish</td>
<td>81,000</td>
<td>1 Kg</td>
<td>81,000</td>
</tr>
<tr>
<td>Meat (mixed cut)</td>
<td>20,300</td>
<td>4 Kgs</td>
<td>81,200</td>
</tr>
<tr>
<td>Eggs</td>
<td>8,300</td>
<td>2 Units</td>
<td>16,600</td>
</tr>
<tr>
<td>Vegetables (greens)</td>
<td>5,700</td>
<td>7.5 Kgs</td>
<td>42,750</td>
</tr>
<tr>
<td>Tomato</td>
<td>7,500</td>
<td>4 Kgs</td>
<td>30,000</td>
</tr>
<tr>
<td>Onion</td>
<td>7,400</td>
<td>4 Kgs</td>
<td>29,600</td>
</tr>
<tr>
<td>Milk (fresh)</td>
<td>12,200</td>
<td>1 x 2 litres</td>
<td>12,200</td>
</tr>
<tr>
<td>Cooking oil</td>
<td>29,200</td>
<td>2 x 2 litres</td>
<td>58,400</td>
</tr>
<tr>
<td>Bread</td>
<td>3,800</td>
<td>1 loaf/day</td>
<td>114,000</td>
</tr>
<tr>
<td>Sugar</td>
<td>6,400</td>
<td>8 Kgs</td>
<td>51,200</td>
</tr>
<tr>
<td>Salt</td>
<td>3,300</td>
<td>1 Kg</td>
<td>3,300</td>
</tr>
<tr>
<td>Tea (leaves)</td>
<td>11,500</td>
<td>1 x 500 g</td>
<td>11,500</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>K901,250</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(B) COST OF ESSENTIAL NON-FOOD ITEMS

<table>
<thead>
<tr>
<th>Item</th>
<th>Kwacha</th>
<th>Quantity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charcoal</td>
<td>72,500</td>
<td>2 x 90 Kg bags</td>
<td>145,000</td>
</tr>
<tr>
<td>Soap (lifebuoy)</td>
<td>2,500</td>
<td>10 tablets</td>
<td>25,000</td>
</tr>
<tr>
<td>Wash soap (Bruce)</td>
<td>4,000</td>
<td>4 x 400 g</td>
<td>16,000</td>
</tr>
<tr>
<td>Jelly (e.g., Vaseline)</td>
<td>6,900</td>
<td>1 x 500 ml</td>
<td>6,900</td>
</tr>
<tr>
<td>Electricity (medium density)</td>
<td>70,000</td>
<td>300 units</td>
<td>70,000</td>
</tr>
<tr>
<td>Water &amp; Sanitation (med - fixed)</td>
<td>114,530</td>
<td></td>
<td>114,530</td>
</tr>
<tr>
<td>Housing (medium density)</td>
<td>1,500,000</td>
<td></td>
<td>1,500,000</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>K1,877,430</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Totals from previous months</th>
<th>Apr 09</th>
<th>May 09</th>
<th>Jun 09</th>
<th>Jul 09</th>
<th>Aug 09</th>
<th>Sep 09</th>
<th>Oct 09</th>
<th>Nov 09</th>
<th>Dec 09</th>
<th>Jan 10</th>
<th>Feb 10</th>
<th>Mar 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amount</td>
<td>2,219,230</td>
<td>2,249,280</td>
<td>2,166,780</td>
<td>2,226,930</td>
<td>2,235,780</td>
<td>2,266,680</td>
<td>2,200,630</td>
<td>2,254,630</td>
<td>2,276,730</td>
<td>2,096,650</td>
<td>2,713,580</td>
<td>2,778,600</td>
</tr>
</tbody>
</table>

(C) SOME OTHER ADDITIONAL COSTS

<table>
<thead>
<tr>
<th>Item</th>
<th>Kwacha</th>
<th>Item</th>
<th>Kwacha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>K300, 000 – K420, 000</td>
<td>Transport (bus fare round trip): Chilenge-Town</td>
<td>K6, 000</td>
</tr>
<tr>
<td>Grades 8-9 (User+PTA/year)</td>
<td>K600, 000 – K900, 000</td>
<td>Chilenge-Town</td>
<td>K6, 000</td>
</tr>
<tr>
<td>Grades 10-12 (User+PTA/year)</td>
<td>K600, 000 – K900, 000</td>
<td>Chembe-Town</td>
<td>K7, 000</td>
</tr>
<tr>
<td>School Uniform (grades 8-12)</td>
<td>K90, 000 – K180, 000</td>
<td>Matero-Town</td>
<td>K5, 400</td>
</tr>
<tr>
<td>Health (clinic)</td>
<td></td>
<td>Fuel (cost at the pump)</td>
<td></td>
</tr>
<tr>
<td>3 Month Scheme (per person)</td>
<td>K5, 000</td>
<td>Petrol (per litre)</td>
<td>K6, 691</td>
</tr>
<tr>
<td>No Scheme Emergency Fee</td>
<td>K5, 500</td>
<td>Diesel (per litre)</td>
<td>K6, 300</td>
</tr>
<tr>
<td>Mosquito Net (private)</td>
<td>K15, 000 – K20, 000</td>
<td>Paraffin (per litre)</td>
<td></td>
</tr>
</tbody>
</table>

(D) SOME COMPARATIVE FIGURES OF WAGES—"TAKE HOME PAY"

<table>
<thead>
<tr>
<th>Pay Slip</th>
<th>Teacher</th>
<th>Nurse</th>
<th>Guard with Security Firm</th>
<th>Secretary in Civil Service</th>
<th>Average Monthly Income in Urban Low Cost Area - CSO</th>
<th>Pieceworker on a Farm</th>
</tr>
</thead>
<tbody>
<tr>
<td>K1,186,300 to K1,881,600</td>
<td>K1,221,000 to K2,874,000</td>
<td>K250,000 to K850,000</td>
<td>K780,000 to K1,520,127</td>
<td>645,326 (between October 2004 and January 2005)</td>
<td>K5,000 to K15,000 per day</td>
<td></td>
</tr>
</tbody>
</table>

This survey was conducted on 30 April 2010 by the Social Conditions Programme of the Jesuit Centre for Theological Reflection. Average prices were calculated on the basis of prices gathered from retail outlets at Northmead, Shoprite (Katuba Road), and City Market, Chawama, Chinthe, Kabwata, Matero and schools. clinics/hospitals around Lusaka. The April Basic Needs Basket is approximately US$585 based on an average middle exchange rate of 1430 Kwacha per US$ at the end of April.

Jesuit Centre for Theological Reflection, P.O. Box 37774, 10101 Lusaka, Zambia
Tel: 260-211-299-410 Fax: 260-211-299-759 E-mail: soc@ccfr.zam Internet: www.jcfr.org.zm Location: Luwisha House, Plot 5880 Great East Road opposite UNZA main gates, Lusaka

190
## JCTR Basic Needs Basket: Lusaka

**March 2011**

### (A) Cost of Basic Food Items for a Family of Six in Lusaka

<table>
<thead>
<tr>
<th>Commodity</th>
<th>Kwacha</th>
<th>Quantity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mealie meal (breakfast)</td>
<td>49,300</td>
<td>3 x 25 Kg bags</td>
<td>147,900</td>
</tr>
<tr>
<td>Beans</td>
<td>8,700</td>
<td>2 Kgs</td>
<td>17,400</td>
</tr>
<tr>
<td>Kapenta (Siavonga)</td>
<td>100,300</td>
<td>2 Kgs</td>
<td>200,600</td>
</tr>
<tr>
<td>Dry Fish</td>
<td>100,000</td>
<td>1 Kg</td>
<td>100,000</td>
</tr>
<tr>
<td>Meat (mixed cut)</td>
<td>28,700</td>
<td>4 Kgs</td>
<td>114,800</td>
</tr>
<tr>
<td>Eggs</td>
<td>8,400</td>
<td>2 Units</td>
<td>16,800</td>
</tr>
<tr>
<td>Vegetables (greens)</td>
<td>4,400</td>
<td>7.5 Kgs</td>
<td>33,000</td>
</tr>
<tr>
<td>Tomato</td>
<td>5,200</td>
<td>4 Kgs</td>
<td>20,800</td>
</tr>
<tr>
<td>Onion</td>
<td>8,000</td>
<td>4Kgs</td>
<td>32,000</td>
</tr>
<tr>
<td>Milk (fresh)</td>
<td>14,200</td>
<td>1 x 2 litres</td>
<td>14,200</td>
</tr>
<tr>
<td>Cooking oil</td>
<td>29,300</td>
<td>2 x 2 litres</td>
<td>58,600</td>
</tr>
<tr>
<td>Bread</td>
<td>4,200</td>
<td>1 loaf/day</td>
<td>120,000</td>
</tr>
<tr>
<td>Sugar</td>
<td>6,300</td>
<td>8 Kgs</td>
<td>50,400</td>
</tr>
<tr>
<td>Salt</td>
<td>3,200</td>
<td>1 Kg</td>
<td>3,200</td>
</tr>
<tr>
<td>Tea (leaves)</td>
<td>9,700</td>
<td>1 x 500 g</td>
<td>9,700</td>
</tr>
</tbody>
</table>

Sub-total **K945,400**

### (B) Cost of Essential Non-Food Items

<table>
<thead>
<tr>
<th>Item</th>
<th>Kwacha</th>
<th>Description</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charcoal</td>
<td>83,600</td>
<td>2 x 90 Kg bags</td>
<td>167,200</td>
</tr>
<tr>
<td>Soap (tub enthusiastically)</td>
<td>3,100</td>
<td>10 tablets</td>
<td>31,000</td>
</tr>
<tr>
<td>Wash soap (Boom)</td>
<td>4,300</td>
<td>4 x 400 g</td>
<td>17,200</td>
</tr>
<tr>
<td>Jelly (e.g., Vaseline)</td>
<td>8,000</td>
<td>1 x 500 ml</td>
<td>8,000</td>
</tr>
<tr>
<td>Electricity (medium density)</td>
<td>130,000</td>
<td>300 units</td>
<td>130,000</td>
</tr>
<tr>
<td>Water &amp; Sanitation (med - fixed)</td>
<td>210,000</td>
<td></td>
<td>210,000</td>
</tr>
<tr>
<td>Housing (medium density)</td>
<td>1,500,000</td>
<td></td>
<td>1,500,000</td>
</tr>
</tbody>
</table>

Sub-total **K2,063,400**

Total for Basic Needs Basket **K3,008,800**

*Note that the cost of housing has not been adjusted because research and consultations are still ongoing.

<table>
<thead>
<tr>
<th>Month</th>
<th>Mar 10</th>
<th>Apr 10</th>
<th>May 10</th>
<th>Jun 10</th>
<th>Jul 10</th>
<th>Aug 10</th>
<th>Sep 10</th>
<th>Oct 09</th>
<th>Nov 10</th>
<th>Dec 10</th>
<th>Jan 11</th>
<th>Feb 11</th>
</tr>
</thead>
</table>

### (C) Some Other Additional Costs

<table>
<thead>
<tr>
<th>Item</th>
<th>Kwacha</th>
<th>Description</th>
<th>Kwacha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grades 8-9 (User+PTA/year)</td>
<td>K350,000</td>
<td>K470,000</td>
<td>K6,000</td>
</tr>
<tr>
<td>Grades 10-12 (User+PTA/year)</td>
<td>K600,000</td>
<td>K800,000</td>
<td>K7,000</td>
</tr>
<tr>
<td>School Uniform (grades 8-12)</td>
<td>K80,000</td>
<td>K200,000</td>
<td>K5,400</td>
</tr>
<tr>
<td>Health (clinic)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fuel (cost at pumping)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Month Scheme (per person)</td>
<td>K5,000</td>
<td>Petrol (per litre)</td>
<td>K7,639</td>
</tr>
<tr>
<td>No Scheme Emergency Fee</td>
<td>K5,500</td>
<td>Diesel (per litre)</td>
<td>K6,999</td>
</tr>
<tr>
<td>Mosquito Net (private)</td>
<td>K30,000</td>
<td>K120,000</td>
<td>K5,030</td>
</tr>
</tbody>
</table>

### (D) Some Comparative Figures of Wages—“Take Home Pay”

<table>
<thead>
<tr>
<th>Teacher</th>
<th>Kwacha</th>
<th>Description</th>
<th>Kwacha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pay Slip</td>
<td>K1,300,000 to K2,000,000</td>
<td>K1,300,000 to K2,000,000</td>
<td>K250,000 to K350,000</td>
</tr>
<tr>
<td>Secretary</td>
<td>K1,300,000 to K2,000,000</td>
<td>K1,000,000 to K1,450,000</td>
<td>K5,000 to K15,000 per day</td>
</tr>
<tr>
<td>Average Monthly Income in Urban Low-Cost Area - CUZD</td>
<td>K1,900,000</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*This survey was conducted on 28 & 29 March 2011 by the Social Conditions Programme of the Jesuit Centre for Theological Reflection. Average prices were calculated on the basis of prices gathered from retail outlets at Northmead, Shimpeta (Kutale Road), and City Market, Chawama, Chinda, Kabwata, Matero and schools. clinics/hospitals around Lusaka. The March Basic Needs Basket is approximately US$148 based upon an average middle exchange rate of 4717 Kwacha per US$ at the end of March.*
**JCTR BASIC NEEDS BASKET: LUSAKA**

**April 2012**

(A) **COST OF BASIC FOOD ITEMS FOR A FAMILY OF FIVE IN LUSAKA**

<table>
<thead>
<tr>
<th>Commodity</th>
<th>Kwacha</th>
<th>Quantity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mealie Meal (breakfast)</td>
<td>40,400</td>
<td>2 x 25 Kg bags</td>
<td>80,800</td>
</tr>
<tr>
<td>Beans</td>
<td>11,500</td>
<td>3 Kgs</td>
<td>33,300</td>
</tr>
<tr>
<td>Kapenta (Siyavonga)</td>
<td>85,300</td>
<td>2 Kgs</td>
<td>170,600</td>
</tr>
<tr>
<td>Dry Fish</td>
<td>45,000</td>
<td>1 Kg</td>
<td>45,000</td>
</tr>
<tr>
<td>Meat (mixed cut)</td>
<td>25,000</td>
<td>4 Kgs</td>
<td>100,000</td>
</tr>
<tr>
<td>Eggs</td>
<td>7,700</td>
<td>2 Units</td>
<td>15,400</td>
</tr>
<tr>
<td>Vegetables (greens)</td>
<td>5,800</td>
<td>4 Kgs</td>
<td>23,200</td>
</tr>
<tr>
<td>Tomato</td>
<td>5,400</td>
<td>4 Kgs</td>
<td>21,600</td>
</tr>
<tr>
<td>Onion</td>
<td>5,600</td>
<td>2 Kgs</td>
<td>11,200</td>
</tr>
<tr>
<td>Milk (fresh)</td>
<td>5,000</td>
<td>4 x 500ml</td>
<td>20,000</td>
</tr>
<tr>
<td>Cooking oil</td>
<td>34,700</td>
<td>3 litres</td>
<td>41,640</td>
</tr>
<tr>
<td>Bread</td>
<td>4,400</td>
<td>1 loaf/day</td>
<td>132,000</td>
</tr>
<tr>
<td>Sugar</td>
<td>13,600</td>
<td>3 x 2 Kgs</td>
<td>40,800</td>
</tr>
<tr>
<td>Salt</td>
<td>3,300</td>
<td>1 Kg</td>
<td>3,300</td>
</tr>
<tr>
<td>Tea (leaves)</td>
<td>38,000</td>
<td>1 Kg</td>
<td>38,000</td>
</tr>
</tbody>
</table>

**Sub-total**

K776,840

(B) **COST OF ESSENTIAL NON-FOOD ITEMS**

<table>
<thead>
<tr>
<th>Item</th>
<th>Kwacha</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Charcoal</td>
<td>118,000</td>
<td>2 x 90 Kg bags</td>
<td>236,000</td>
</tr>
<tr>
<td>Soap (Lifeway)</td>
<td>2,700</td>
<td>10 tables</td>
<td>27,000</td>
</tr>
<tr>
<td>Wash soap (Broom)</td>
<td>4,200</td>
<td>4 x 400 g</td>
<td>16,800</td>
</tr>
<tr>
<td>Jelly</td>
<td>10,000</td>
<td>1 x 500 ml</td>
<td>10,000</td>
</tr>
<tr>
<td>Electricity (medium - fixed)</td>
<td>130,000</td>
<td></td>
<td>130,000</td>
</tr>
<tr>
<td>Water &amp; Sanitation (med - fixed)</td>
<td>210,000</td>
<td></td>
<td>210,000</td>
</tr>
<tr>
<td>Housing (3 bedrooms)</td>
<td>1,500,000</td>
<td></td>
<td>1,500,000</td>
</tr>
</tbody>
</table>

**Sub-total**

K2,130,700

**Total for Basic Needs Basket**

K2,907,540

*Note that the cost of housing has not been adjusted because research and consultations are still ongoing*

<table>
<thead>
<tr>
<th>Month</th>
<th>April</th>
<th>May</th>
<th>June</th>
<th>July</th>
<th>Aug</th>
<th>Sep</th>
<th>Oct</th>
<th>Nov</th>
<th>Dec</th>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
</tr>
</thead>
</table>

(C) **SOME OTHER ADDITIONAL COSTS**

<table>
<thead>
<tr>
<th>Item</th>
<th>Kwacha</th>
<th>Item</th>
<th>Kwacha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>K400,000-1,000,000</td>
<td>Transport (bus fare round-trip): Chilengi-Town</td>
<td>K7, 200</td>
</tr>
<tr>
<td>Grades 8-12 (User + PTA/year)</td>
<td>K650,000 - K1,000,000</td>
<td>Chelston - Town</td>
<td>K8, 000</td>
</tr>
<tr>
<td>School Uniform (grades 8-12)</td>
<td>K100,000 - K200,000</td>
<td>Matero-Town</td>
<td>K7, 000</td>
</tr>
<tr>
<td>Health (clinic)</td>
<td></td>
<td>Fuel (cost at the pump)</td>
<td></td>
</tr>
<tr>
<td>Registration (book)</td>
<td>K3,000 - K5,000</td>
<td>Petrol (per litre)</td>
<td>K8, 155</td>
</tr>
<tr>
<td>Self referred (Emergency Fee)</td>
<td>K5, 500</td>
<td>Diesel (per litre)</td>
<td>K7, 566</td>
</tr>
<tr>
<td>Mosquito Net (private)</td>
<td>K30,000 - K120,000</td>
<td>Paraffin (per litre)</td>
<td>K5, 154</td>
</tr>
</tbody>
</table>

(D) **SOME COMPARATIVE FIGURES OF WAGES—“TAKE HOME PAY”**

<table>
<thead>
<tr>
<th>Teacher Name</th>
<th>Kwacha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pay Slip</td>
<td>K1,300,500 to K1,500,000</td>
</tr>
</tbody>
</table>

**Note that the adjusted wages for civil service workers has not been adjusted because consultations are still ongoing**

This survey was conducted on 26th April, 2012 by the Social Conditions Programme of the Jesuit Centre for Theological Reflection. Average prices were calculated on the basis of prices gathered from retail outlets at Northmead, Chipata (Gazo Road), and City Market, Chilengi, Chinda, Kabwata, Matero and schools, clinics, hospitals around Lusaka. The April Basic Needs Basket is approximately US$559 based upon an average middle exchange rate of $200 Kwacha per US$ at the end of April.

Jesuit Centre for Theological Reflection, P.O. Box 37774, 10101 Lusaka, Zambia